THE ROLE OF OLDER PERSONS IN THE MANAGEMENT OF HIV AND AIDS: AN ASSESSMENT OF THEIR CONTRIBUTION AND SUPPORT NEEDS IN THREE SOUTH AFRICAN PROVINCES

GEORGE SABELA PETROS

Dissertation prepared for the degree of

DOCTOR OF PHILOSOPHY

in the School of Public Health and Family Medicine

UNIVERSITY OF CAPE TOWN

May 2010

DECLARATION

I, THE UNDERSIGNED, HEREBY DECLARE THAT THE WORK CONTAINED IN THIS DISSERTATION IS MY OWN WORK, EXCEPT WHERE DUE ACKNOWLEDGMENT IS MADE WITH FULL REFERENCES IN THE TEXT AND IT HAS NOT PREVIOUSLY BEEN SUBMITTED TO ANY UNIVERSITY OR INSTITUTION OF HIGHER LEARNING FOR ANY QUALIFICATION OR CERTIFICATE.

……..
SABELA GEORGE PETROS

ACKNOWLEDGEMENTS

This dissertation would not have been possible if older persons (*gogos*) were not carrying the burden of the HIV and AIDS epidemics in sub-Saharan Africa. My sincere gratitude goes to the fieldworkers who gathered the data under difficult circumstances. Special thanks go to Mrs Dorothy Shangase (KwaZulu-Natal), Mrs Noloyiso Tileng (Western Cape) and Mrs Susan Siwahla (Eastern Cape) who supervised the fieldwork in the three provinces. I am grateful to the boards and management teams of the non-profit organisations that gave me access to their records and clients.

My deepest gratitude goes to my supervisors Professors Monica Ferreira and Rodney Ehrlich, who contributed time, critical support and expertise to help me to develop a fuzzy idea into an academically respectable dissertation.

My thanks also go to the Institute of Ageing in Africa at the University of Cape Town for general support and to Zameka Ndzotyana for help in formatting the tables in this dissertation.

I would like to thank the Human Sciences Research Council HSRC/Nelson Mandela Foundation for believing in me and providing seed money to conduct the empirical study.

I wish to express my sincere appreciation to the managers and co-ordinators of the non profit organisations, and senior government officials who spent their time and energy answering searching policy questions I posed to them.

Finally, my fond thanks go to Nolwandle Mngqundaniso for her unshakeable support through all the incidents and accidents I encountered during the conceptualisation of and numerous drafts I wrote for this work, and to my family for their understanding when I had to miss numerous important family gatherings to focus on the dissertation.

TABLE OF CONTENTS

Page

CHAPTER SEVEN: CONCLUSIONS, EVALUATION AND RECOMMENDATIONS

Page

LIST OF TABLES

LIST OF FIGURES

Page

LIST OF ANNEXURES

Page

LIST OF ANNEXURES

LIST OF FIGURES

Page

LIST OF TABLES

LIST OF FIGURES

Page

LIST OF ANNEXURES

CHAPTER ONE: THE CONTEXT AND MOTIVATION FOR A STUDY

1.1 STATEMENT OF THE PROBLEM

The effects of HIV and AIDS on households and caregivers, in particular households in which older persons reside and are caregivers to persons living with HIV and AIDS (PLWHA) and orphaned and vulnerable children (OVC), are not well understood. Neither is it adequately known what the support needs of older carers are to help them to cope with the multiple effects of the disease. An investigation is indicated to fill a gap in knowledge in this subject area, and to provide empirical evidence to inform governments and other relevant stakeholders in the development of appropriate policy and programmatic responses to support older caregivers.

It is more than two decades since the HI virus and its disease condition AIDS were identified (Mann, 1989), and awareness of dire effects of the disease started to grow. In 2007, an estimated 33 million people globally were living with HIV (UNAIDS, 2008). The pandemic has resulted in massive suffering and loss of life in many parts of the world, but especially in sub-Saharan Africa and in South Africa in particular. Little more than a tenth of the world's population lives in sub-Saharan Africa, but the region is home to almost 67 per cent of all people living with HIV and AIDS (PLWHA), and has experienced 72 per cent of all AIDS defining deaths (UNAIDS, 2006; UNAIDS, 2008). In 2006, an estimated 2.7 million people in the region were newly infected with the virus, and 2 million adults and children had died of AIDS related conditions (UNAIDS, 2006). Three quarters of females (age 15 years and over) living with HIV worldwide are in the sub-region. In South Africa, almost one in three pregnant women attending public antenatal clinics in 2004 were HIV positive; trends show a gradual increase in HIV prevalence in South African females, albeit with a slight decline in 2006 (Department of Health (South Africa), 2007). Across provinces, the prevalence of HIV is higher, for example, in KwaZulu-Natal (39.1%) than in the Eastern Cape (29.0%) and the Western Cape (15.2%) (Department of Health (South Africa), 2006). Therefore, comparing the three provinces could provide useful information for the development of a policy framework on HIV and AIDS caregiving relevant to South Africa.

Research shows that 90 per cent of care for PLWHA globally is provided at home – in SSA, mainly by older persons. In addition, older persons provide surrogate care to an increasing

number of orphaned and vulnerable children (OVC) – mainly their grandchildren (Ferreira et al., 2001; HelpAge International (HAI), 2003a; World Health Organization (WHO), 2002a, 2000; Uys, 2003; Knodel et al., 2006). Although studies have been conducted in some southern African countries on the effects of HIV and AIDS on older persons, the majority of the studies have been small-scale and localised (Ogden et al., 2005; WHO, 2005; Schatz, 2007; Ferreira et al., 2001). Governments at national, provincial and local, or district levels have thus far neither recognised nor acknowledged the critical role that older persons play in managing HIV and AIDS at a household and community level, nor consulted them or incorporated them in policies and programmes on HIV and AIDS (HAI, 2005a).

Government policies and programmes designed and implemented to mitigate the effects of HIV and AIDS have thus far focused on young people of reproductive age, and have not addressed the information needs of older persons (HAI, 2006a). Older persons are neither targeted in awareness programmes nor supported in their care responsibilities; in short, they are ill-equipped to cope with the burden of care in general (HAI, 2006a; Knodel, 2006; WHO, 2000). It is commonplace for older persons to conceal the presence of the disease in their household, for fear of stigmatisation, discrimination and ostracism in the community; in so doing, such persons and households forego opportunities to receive support from the community. Older persons who care for PLWHA and OVC are often unable, moreover, to continue to engage in income generation activities, to support themselves and their household, because of their advancing age, age discrimination in the workplace, and/or their care responsibilities (Caliandro & Hughes, 1998; Lesar et al., 1995; Steinberg et al., 2002). A general lack of resources, stress related to caregiving, funeral costs when PLWHA die and support for bereaved grandchildren are major concerns to older caregivers (Ferreira et al., 2001; Steinberg et al., 2002; Akintola, 2004).

In recognition of the multiple challenges that older persons in AIDS affected households face, international bodies such as the HelpAge International (HAI, 2003a) have emphasised a need for evidence through research to inform appropriate responses to the effects of the disease on older persons, both as a group at risk of infection and in the crucial role they play as primary carers. Older carers are a valuable care resource to their family, and contribute to development in numerous ways, but their contributions need to be supported and sustained. Unfortunately, policy makers commonly take older persons' contributions for granted. When

older persons are included in strategies to address HIV and AIDS related problems, it is likely to be more by default than design (Ogden et al., 2004).

"Care" provided by older persons in households affected by HIV and AIDS refers to the full range of activities undertaken, including physical care, material support, psychosocial care and support (emotional and spiritual), custodial care (cooking, cleaning, feeding, grooming, helping with toilet needs, etc.), socialisation of young children in their care, health care, and the administration of medications and treatments. In the course of caring for HIV infected adult children and infected grandchildren, older persons are exposed to a risk of contracting the virus and opportunistic infections themselves, due to poor knowledge and understanding on how to care for PLWHA and to protect themselves. Ultimately, the PLWHA for whom they care will die, leaving the carer without support that he or she may have anticipated in old age (WHO, 2002; ASSOM, 2005).

The effects of HIV and AIDS on older persons' households are thus multiple and cumulative, and drain households' resources progressively over time. This situation poses a number of challenges to governments, societies, families and individuals in settings with scarce resources, common or even typical in Africa, including South Africa. Traditional safety nets such as the extended family, that would otherwise have enabled affected families to remain financially stable, are increasingly over stretched (Carballo & Carael, 1988; PANOS, 1990; Taylor et al., 1996). Social capital from which affected households might draw assistance and support, such as family and community members, is diminishing, in part due to AIDS associated mortality, other demographic and social change, and fear of stigma associated with HIV and AIDS (Steinberg et al., 2002). Households with a low level of kin support, or no such support, affected by the disease sometimes face dissolution, as some family members die and others disperse (Barnett & Blakkie, 1992; UN, 2006). Young children may be relocated elsewhere to be cared for by other relatives when their parent(s) die, but research has shown that it is in the children's best interest to grow up in their family home (UN, 2004a). Hence, the support of older carers to enable them to sustain their households and keep them intact is an important consideration as well.

HIV and AIDS policies and programmes need to take account not only of the roles that older persons play and the contributions they make in mitigating the effects of the AIDS epidemic, but also incorporate their multiple socio-economic, health and psychosocial needs in the

design and implementation of appropriate responses. Thus, older carers' contributions and support needs should be integrated in strategies and programmes that can sustain their health and support their well-being, in addition to meeting the needs of other target groups, such as PLWHA and OVC, and other members of the carer's household (UN, 2004). The inclusion of older persons in responses are indicated moreover in terms of universal human rights, provided for, for example, in South Africa's constitution, such as the right of all citizens to equal health and preventive care, and support and treatment (South African Constitution, 1996; UN, 2004a). Yet, their right to information is neither honoured, nor are older persons mentioned in information issued by governments in responses to HIV and AIDS, or in the media, and neither are they targeted in anti-AIDS campaigns (HAI, 2005c).

This dissertation will examine the impact of HIV and AIDS on older persons who care for adult children living with AIDS (PLWHA) and orphaned and vulnerable grandchildren (OVC). A main aim will be to provide empirical evidence to inform appropriate policy development and programme design and implementation to support the needs of older persons who contribute substantially to the care management of the epidemic at community and household levels, and who are rendered vulnerable by effects of the epidemics. It will be argued in the dissertation that the provision of appropriate support to older persons and their households in South Africa may be best co-ordinated and offered through a Primary Health Care (PHC) approach at the district level. The multi-dimensional problems presented by HIV and AIDS require complex approaches to address them. Primary Health Care, with its fundamental principle of a comprehensive approach to address health problems (WHO, 1978), can offer an appropriate framework within which policy and programmatic responses to the needs of older caregivers may be developed, co-ordinated and implemented.

The results of an empirical study, to be conducted as part of the dissertation, will be used to develop a policy framework within a PHC context, as an overall outcome of the study and dissertation. The framework will promote and guide collaboration among stakeholders at the district level: between non-profit organisations (NPOs), community-based organisations (CBOs), faith-based organisations (FBOs), traditional healers, government structures and business, to provide support to older person headed households and families. The study outcomes and the policy framework may be used moreover by stakeholders to encourage lobbying of government ministries to mainstream the support needs of older carers in their programmes and policies, and to close gaps in existing policies. Alternatively, specific

policies and programmes may be developed for this purpose. Recommendations will be made in the dissertation, based on the study outcomes, on how the role and contribution of older persons in the management of the epidemic at the household level may be acknowledged and strengthened, and their caregiving optimised, to better promote, prevent and manage HIV and AIDS in a comprehensive manner at the district level**.**

1.2 EFFORTS TO CONTAIN HIV AND AIDS, AND SUPPORT OLDER CARERS

1.2.1 Policies, programmes and responses

A range of international instruments, such as the Millennium Declaration (UN, 2000) and the subsequent Millennium Development Goals (MDGs) (UN, 2002), developed by global bodies - in this case within the United Nations system, are available, and a large number of Member States, including South Africa, are signatories to the instruments. While governments globally have committed themselves to combating the AIDS pandemic by 2015 (UN, 2001a), much still needs to be done to mitigate the effects of the epidemic on families and households before the goals are achieved. Combating the pandemic is one of the MDG goals, all of which are aimed at development. Older women bear a disproportionate burden of care and support of PLWHA and OVC, and they contribute to development in these ways. However, the burden of care has deleterious consequences for their health and well-being (Ferreira, 2001; WHO, 2002; Akintola, 2004). Thus far, government policies and programmes, especially in South Africa, have done little or nothing to integrate older persons as a care resource and change agents, or agents for development in the fight against the epidemic, or to support their contributions.

The lack of a medical cure for HIV has forced governments globally to emphasise prevention as a response to the pandemic. Only in a few SSA countries has there been strong support for the roll-out of anti-retroviral therapy (ART) – notably Botswana, Malawi, Uganda, Zambia and Zimbabwe, and more recently South Africa (PEPFAR, 2008). Other governments in SSA have tended to rely on prevention programmes, mainly due to the unaffordability of the anti-retroviral drugs, and a lack of infrastructure and suitably qualified personnel to implement therapeutic programmes (AED-USAID, 2003; Esu-Williams, 2003; Akintola, 2004; ASSOM, 2005). The South African government also puts a strong emphasis on prevention, among which are awareness campaigns, the distribution of condoms, the dissemination of

information, voluntary counselling and testing (VCT), the prevention of mother to child transmission (PMTCT), and the treatment of sexually transmitted infections (STIs) (HIV/AIDS and Strategic Plan for South Africa, 2000-2005); older persons have been excluded in all these programmes. These preventive measures alone have not been able to contain the spiralling epidemic in South Africa. Successive Government HIV and Syphilis Ante-Natal Clinic (ANC) surveys indicate that HIV prevalence estimates among the adult population are increasing: from 26.5 per cent in 2002, to 27.9 per cent in 2003, to 29.5 per cent in 2004, to 30.2 per cent in 2005, but with a slight decline, to 29.1 per cent, in 2006 (Makhubalo et al., 2004; DoH, 2007). As a consequence of these high prevalence rates, the under resourced public health system is overstretched, and cannot cope with the increasing number of AIDS related cases (Shisana et al., 2003; De Jong, 2003). In many cases it responds by discharging patients early, to be cared for in the community, mainly by an older relative (Johnson et al., 2002). Unfortunately, when patients have been discharged to be managed at the community level, AIDS treatment has been unsatisfactory, either owing to earlier government contestation of proven efficacy of anti-retroviral (ARV) drugs in containing the spread of the disease or slow rollout of treatment and infrastructure. Nonetheless, the situation is changing, with the appointment of a new health minister in 2008, who supports and facilitates a wide roll-out of ARV treatment within the public health sector. South Africa has shown some improvement in ARV coverage, from 2 per cent in 2004 to 28 per cent in 2008. However, the coverage is still viewed as poor, since only slightly over a quarter of PLWHA who need the treatment get it (*Cape Argus*, 2008:16).

Despite the increasing demands that HIV and AIDS are placing on overstretched public health systems, the burden of care engendered by the epidemics in truth reflects only a fraction of the total number of people in need of care for HIV-related illnesses, as those diagnosed with the virus are a minority of the total number of infected persons (UNAIDS, 2002). Most PLWHA and their caregivers will seek symptomatic relief from pharmacies or treatment from out-patient clinics or a doctor's surgery initially. As the chronic nature of the illness becomes apparent, some will seek treatment from traditional healers (Creswell, 1998; Ankrah, 1991; Osborne, 1996; Peltzer et al., 2005). Caregivers and PLWHA who know or suspect they are infected with the virus may be reluctant moreover to seek care in the public health sector, for a variety of reasons, including a lack of privacy, stigma and fear of depersonalising attitudes of health care providers (Jewkes et al., 1998; Ogden et al., 2004).

Although older persons involved in the management of the epidemics are a crucial resource for the support of PLWHA, they lack appropriate information and skills training, and other resources, such as finance. Thus, while they play a crucial part in a broad continuum of care that enables the referral of PLWHA between different levels of care (Jackson, 2002), public health systems have in effect shifted the responsibility of care to ill-equipped and poorly resourced communities and households, which is an untenable solution to the problem of HIV and AIDS caregiving.

1.2.2 A shift from hospital-based care, to care in the community and households

The United Nations system, bilateral donors, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and governments of affected countries increasingly focus on treatment and care, rather than prevention, as part of their commitment to scaling up the global response to HIV (UNAIDS, 2004a). Public health policy makers have realised that public health systems are unable to manage AIDS-related morbidity, and in the mid 1990s began to consider ways to shift the locus of clinical care from hospitals to health services in the community (Ogden et al., 2004). Initially, hospital based outreach programmes were favoured, whereby hospital staff travelled to patients' homes to provide care. The justification for the hospital initiated home-care models was that, given the limited treatment available in hospitals for many hospitalised AIDS patients, it was neither in the health services' nor the patients' interests for them to be in hospital (Osborne, 1996). Although these home-based programmes were found to be time consuming and expensive, especially in rural areas (Chela, 1995), in most worst affected countries, such as Malawi, South Africa and Uganda, the programmes are still implemented as an alternative to hospital care (Akintola, 2004; ASSOM, 2005; Jackson, 2002; Ogden et al., 2004).

As the public health sector in many SSA countries gradually shifts its provision of care services to PLWHA to communities, arguing that it is in the patients' best interest to be cared for by kin – but in effect absolving itself of these responsibilities, the South African government with the assistance of the European Union (EU) has begun recruiting and funding non-profit organisations (NPOs) to provide home based care (HBC) to affected communities and households (Peltzer et al., n.d). Most of these NPOs provide holistic, or comprehensive care, which addresses all of a patient's needs, and the needs of family carers and OVC to some extent (Jackson, 2002). The majority of the HBC programmes were started

as a response to an increasing need in communities to provide care for PLWHA, who otherwise would not be cared for adequately. They are mainly staffed by local volunteers affiliated to religious groups motivated by compassion (USAID, 2002; UNAIDS, 2000d; Akintola, 2004).

Although the NPOs' main task is the provision of care to PLWHA, some provide information on HIV awareness and prevention, preparation for the care of orphans, income generation opportunities for the PLWHA's family, and promote legal rights relating to property, inheritance and other matters (Ferreira, 2001; Jackson, 2002; WHO, 2002a). Through regular home visits, service providers are in a position to identify households at high risk of impoverishment, and in which children are vulnerable and will be orphaned. Various models of HBC programmes include hospital mobile outreach, AIDS service organisations, faith-based outreach (FBOs), community-based outreach (CBOs), hospices and PLWHA support organisations (Osborne et al., 1997; Jackson & Anderson, 2001; USAID, 2002), which all form a crucial part of the continuum of care between hospital and the community (Van Praag, n.d.; CEDPA, n.d.). However, the NPOs have low coverage, because of resource constraints, such as finance, a lack of skilled personnel and poor infrastructure, such as office or building space (Jackson, 2002).

1.2.3 Low coverage of HIV and AIDS affected households by under resourced non-profit organisations (NPOs)

In general, non-profit organisations (NPOs) are unable to provide clinical care, but may provide basic nursing care, and a range of other care and support services to PLWHA and affected families. Some services help to improve livelihoods, and provide emotional and spiritual support to groups and individuals (Horizons, 2004). Numerous NPOs have limited resources, depend on volunteers, are not linked to broader resources of support and skills, are overstretched, are characterised as "unsystematic and needs based," and cannot cope with the enormity of the challenges presented by the HIV and AIDS epidemics (Blinkhoff, et al., 1999; Jackson, 2002; WHO, 2002b). In South Africa, some non-profit organisations provide various forms of assistance to older carers in AIDS affected households, such as HIV and AIDS education and information, income generating skills training and opportunities, counselling services, information on legal and human rights related matters for the PLWHA, respite care, and advice on application for social grants. However, coverage of all who need to benefit from NPO programmes can only be improved with full government assistance

(Nsutebu, 2001; WHO, 2002c), through an application of PHC principles, such as inter-sectoral collaboration, to address difficulties faced by older persons households affected by HIV and AIDS.

1.3 POPULATION AGEING

Population ageing and older persons are discussed within the context of demographic transition in sub-Saharan Africa and in South Africa in particular. Factors that contribute to population ageing, and the effects of HIV and AIDS, and migratory patterns on older persons are discussed as well.

1.3.1 Older populations and older persons

Population ageing is a consequence of a continuing demographic transition of unprecedented declines in fertility levels, and lower levels of mortality and increased migration. In the process, the proportion of children and youth in a population shrinks and the proportion of older persons expands (Stloukal, 2001; Marcoux, 2001; Udjo, nd; UNFPA, 2002). Most developed countries began to witness major reductions in the size of their population, first in death rates and subsequently in birth rates, when they started to fail to achieve replacement levels, more than a century ago (UN, 2007a). As the proportion of children in these populations declined, the population structure began to age (UNFPA, 2002). By 2050, the number of older persons in the world will for the first time exceed the number of young people, and most of these persons will live in developing regions such as in Africa (UN, 2001b; UNFPA, 2002) (see Table 1.1).

Different factors contribute to the rapidity of the ageing process in the African continent, predominant among which is a reduction in fertility and, to an extent, AIDS related mortality (UNDP, 2007, Udjo, 2006). The United States of America Census Bureau (USCB, 2005) estimates that the absolute number of people age 50 years and over in sub-Saharan Africa will double from 74 million in 2005 to over 140 million in 2030. However, in contrast to population ageing in the developed world, where the transition occurred slowly and in a well resourced environment, the demographic process in sub-Saharan Africa is occurring rapidly, and in an environment with high levels of poverty and communicable disease, such as HIV and AIDS (Kent & Haub, 2005).

Table 1.1: Size and distribution of the population aged 60 years and over, worldwide, shown separately for more developed countries and less developed countries, 1950–2050

Region	More developed countries		Less developed countries		World
Year	millions	%	Millions	%	Millions
1950	95	46	110	54	205
1970	147	47	165	53	312
2000	232	38	374	62	606
2020	317	31	707	69	1. 024
2050	395	20	1. 569	80	1. 964

Source: Adapted from United Nations (2001) for the medium variant.

Old age is defined variously by different nations and in different regions, influenced to an extent by demographic trends, such as high or low life expectancy, and social, cultural and political factors. The lower cut-off age used for "older persons" by the United Nations is 60 years; this cut-off, rather than the earlier higher cut-off age of 65 years, is now used globally (UNPFA, 2002a). However, in sub-Saharan Africa, chronological age is often a poor yardstick to measure age. Rather, life experience, knowledge of important events and physical appearance (e.g. greying hair) are considered more indicative in denoting an individual as "old" (HAI, 2002b; Nhongo, 2004).

Globally, the older population is growing at a rate of 2.6 per cent per year, faster than the rate of 1.1 percent for the world population as a whole. This trend is expected to continue until 2050. The population aged 60 years and over will moreover grow more rapidly than any other age group (UN, 2007a). In addition, the proportion of older women is expected to increase disproportionately to that of older men in the coming decades, due to significantly higher survival rates of females at every age (UNFPA, 2002a; UN, 2007a). Therefore, by implication, issues of health provision, housing and social protection will be critical for their well-being.

With regard to the SSA region, life expectancy at birth is currently 43 years. However, life expectancy at age 60 in the sub-region is 18.5 years for females and 14.2 years for males (UN, 2007a). In South Africa, life expectancy at birth is 43.8 years for females and 44.2 years for males. At age 60, females can expect to live another 22 years and males, another 17.1 years (UN, 2007a). The relative longevity of older individuals in South Africa, compared to other SSA countries, is thus evident. In the age group 80 years and over, life expectancy for females is 7.4 years and for males 6.4 years for the period 2005-2010 (UN, 2007a). Certainly, AIDS related mortality has reduced life expectancy at birth, but survivors to age 60 may still enjoy longevity.

1.3.1.1 *Older persons in South Africa*

In 2008, South Africa's population aged 60 years and over numbered 3.5 million (Statistics South Africa, 2008). The racial composition of the older population was black Africans 64.2 %, whites 24.3 %, coloureds 8.3 % and Indians/Asians 3.2 %. The ratio of older males to older females was 0.6 (StatsSA, 2008). In the Eastern Cape Province, in 2006, blacks constituted 87.6 % of the older population, and in KwaZulu-Natal 84.4 % and the Western Cape 27.3% (StatsSA, 2006). Table 1.2 below shows the current distribution of older persons by five-year age category, sex and population group in the three provinces in which the empirical study will be conducted. The figures show a decreasing trend in the number of older persons in each age category, from the youngest to the oldest category (above 50 years). Nonetheless, the size of the oldest age group (persons age 80 years and over), especially women, is notably large. These persons may be expected to suffer some physical and/or mental impairment, and co-morbidities, and will require care and support. Thus, the South African government will need to plan to meet the care needs of this age segment through service provision and resource allocation.

Table 1.2: Provincial distribution of persons (age 50+)(1000s), in three provinces in South Africa, by five-year age categories and sex

Age group (years)	Eastern Cape		KwaZulu-Natal		Western Cape		Total		
	Male	Female	Male	Female	Male	Female	Male	Female	Total
50-54	109900	146600	150200	183000	98100	106200	358200	435800	794000
55-59	89200	120900	124800	159200	78800	88800	292800	368900	661700
60-64	83700	111000	106200	135400	71100	78600	261000	325000	586000
65-69	75400	109700	77600	106900	54000	55900	207000	272500	479500
70-74	55500	78200	48000	73200	37800	39200	141300	190600	331900
75-79	32900	47300	28500	48300	20500	22900	81900	118500	200400
80+	23600	40000	20300	37700	14800	23100	58700	100800	159500
Total	470200	653700	555600	743700	375100	414700	1400900	1812100	3213000

Source: Adapted from mid-year population estimates, Statistics South Africa, 2006. (All numbers in this and subsequent population related tables have been rounded off to the nearest thousand, which may lead to small differences in the totals by age and sex.)

Although an expanding older population signifies longevity, which should be viewed as an achievement and not a problem. However, a major challenge in many SSA countries, in particular, is that many older women are faced with the challenges of HIV and AIDS caregiving, late-life parenting, the lack of a spouse, the effects of changing kinship support systems, and a lack of formal, or government support.

Table 1.3 shows the distribution of older persons in urban areas and non-urban areas in the three provinces in which the empirical investigation will be conducted. In terms of absolute numbers, the highest number of older persons resides in KwaZulu-Natal, with an almost equal distribution in urban and non-urban areas. The Eastern Cape Province has the highest proportion of older persons living in non-urban areas, while the Western Cape Province has the highest proportion living in urban areas.

1.3.2 HIV and AIDS, and population ageing in sub-Saharan Africa

The HIV and AIDS epidemics in sub-Saharan Africa continue to change the age profile of this highly affected sub-region (UNPFA, 2002a). It is estimated that by 2025, the size of the total population of the 38 worst affected countries, including South Africa, will be at least 156 million smaller than it would have been in the absence of AIDS, and 58 million children will not have been born because of the early deaths of women of reproductive age (Timaeus, 2004; UN, 2006) (see Table 1.4). The epidemics will therefore affect population growth negatively in the highly affected countries.

South Africa is the most developed country in Africa in terms of economic development. However, although it has a middle-income economy, it has a large third world section of the population, virtually mired in poverty. Nonetheless, it has relatively well developed infrastructure – roads, telecommunication and electricity network – and a developed public health system (see Callaghy, 1993; Therkildsen & Semboja, 1995; Clapham, 1996). It also has the highest AIDS prevalence, after Swaziland (see UNAIDS, 2004a/06).

Table 1.3. Proportional distribution of persons (age 50+) in three provinces of South Africa, by urban area and non-urban area (numbers and percentages)

Eastern Cape			KwaZulu-Natal			Western Cape			Total
Urban	Non-urban	Total	Urban	Non-urban	Total	Urban	Non-urban	Total	
377 238	601 158	978 396	596 287	629 942	1 226 229	626 579	58 883	688 462	**2893087**
38.6%	61.4%		48.6%	51.4%		91.0%	9.0%		

Source: Adapted from the South African Population Census 2001, Statistics South Africa.

.

Table 1.4: Projected effects of HIV and AIDS associated mortality on population size in 38 worst affected sub-Saharan African countries (millions) and population growth rates (percentages), 1995-2025

	Population size (millions)			Annual population growth (percentage)	
	1995	2015	2025	1995-2015	2015-2025
Without AIDS	539	914	1139	2.6	2.2
With AIDS	533	823	983	2.2	1.8
Absolute difference	6	91	91	0.5	0.4
Percentage difference	1	10	14	-	-

Source: UN Population Division: The 2002 revision (UN, 2002).

In South Africa, AIDS associated mortality is starting to affect population ageing: the impact of the epidemic is producing a negative growth rate among the youth compared to the older population (Udjo, 2006). Actuarial Society of South Africa (ASSA) estimates indicate that mortality levels in older persons have stayed fairly constant over the past two decades and will remain so over the next two decades; hence, AIDS related mortality is not yet affecting these levels, to the extent that it is contributing to mortality in the young age groups (ASSA, 2004). However, increased AIDS related mortality levels in infants, children and young adults are having a temporary accelerative effect on population ageing (Joubert et al., 2005).

More important for this dissertation are the consequences of HIV and AIDS associated morbidity and mortality which erode the support base for older persons and bring added caregiving responsibilities to ill-equipped older carers (Ferreira et al., 2001; Johnson et al., 2002; WHO, 2002a). Thus far, the effects and erosion of the support base have received little attention, in either the media or discourse on demographic effects of the diseases on population groups, compared to the attention given to orphans and the youth (Barnett & Whiteside, 2002; UN, 2005). This dissertation thus aims to provide evidence of the multiple losses experienced by affected older persons, which includes the erosion of a support base.

However, research shows that although the prevalence rate of HIV infection in older populations has not been established routinely, older people are nevertheless at risk of infection with the virus (UNAIDS, 2007). Before anti-retroviral therapy (ART) became

widely available, an estimated 6 per cent of the total HIV case load in sub-Saharan Africa was in the population aged 50 years and over (Knodel et al., 2003). Data from the Swaziland Demographic and Health Survey (DHS) (CSO, 2008) indicate an HIV prevalence in the population aged 50 years and over of 14.2 per cent (11.7 % for women, 17.9 % for men). Despite the evidence of older persons' susceptibility to HIV infection, they are overlooked by governments in interventions designed to halt the spread of the disease.

1.3.3 Migration and ageing

In sub-Saharan Africa, migration and the variable circumstances surrounding population movement and disruptions, such as vicious cycles of conflict, poverty and more recently AIDS, contribute to population ageing, especially in rural areas. In South Africa, migration patterns are characterised by a rural-to-urban flow of young adults (especially young African men) who move to cities for better economic and education opportunities (Kok & Collinson, 2006). A consequence of rural-to-urban migration is a "natural increase" of urban populations and a decline in rural populations, primarily due to out-migration and a decline in fertility rates in rural areas. In addition, less out-migration of older persons contributes to the ageing of rural populations (Garenne et al., 2006; Kok & Collinson, 2006; Marcoux, 2001; Skeldon, 1999; Stloukal, 2001).

An exodus of young adults from rural areas translates into hardships for older persons left behind in a poorly resourced rural area, through a loss of able bodied younger persons to help till lands, grow crops and tend livestock (Stloukal, 2001; UN, 2001b; Fouad, 2004; Mba, 2004). When older persons left behind find they can no longer cope on their own, they may follow their kin to an urban area, but where they may experience difficulty in joining kin, and residing in an unfamiliar and often disorganised environment. As a consequence, they may return to their area of origin, or become circular migrants, residing for periods alternately in an urban home and a rural homestead (Kimuna, 2004; Nxusani, 2004).

Young adults too may migrate circularly, which carries a risk that they will become infected with the HI virus in an urban centre and then infect residents of a rural area (UN, 2005). Moreover, when young migrants in an urban area become ill with an AIDS related condition, they tend to return to their rural family home, to be cared for by family, typically an elderly mother, where they will live until they die (Lurie et al., 1997; Knodel, et al. 2002; UNAIDS,

2003; Clark et al., 2005; Garenne et al., 2006). Hence, not only do older persons in rural areas have particular vulnerabilities as a result of a loss of a migrant kin, they must often assume additional livelihood and caregiving responsibilities at a time when they themselves may be becoming dependent and in need of care and support.

1.4 CHANGING FAMILY STRUCTURES AND RELATIONSHIPS

1.4.1 Family structures

The concept of "family" has been defined variously in different societies and cultures (Nzimande, 1996). Contemporary family forms are more fluid than previously, or compared to traditional kin structures in SSA countries, and may be shaped differently in different social, cultural, legal and political contexts. Nonetheless, for the purpose of this dessertation, and a policy intervention to be developed later, the concept of family is defined operationally as a group of kin who co-reside in a house, but other family members may live elsewhere. One of the family members in the household assumes (or is assigned) the role of head of the household. Kin who live elsewhere constitute the extended family (of the co-resident family members). A variety of contemporary family forms in SSA countries are discussed below.

1.4.2 Changes in family structures and relationships

In sub-Saharan Africa, family structures are changing due to a variety of demographic trends, and economic and social factors. Migration is one such trend and factor. As young adults move from a rural area to an urban centre, and establish themselves at the area of destination, the family structure may change from a traditional extended family structure, typical at the area of origin and still predominant in rural areas, to a nuclear family form, increasingly common in urban centres (Jones, 1996). Other evolving, and increasingly common, family forms include skip-generation families where no middle generation family member is present, either because they live elsewhere or have died, increasingly as a result of AIDS (WHO, 2002a). Family members may be widely dispersed moreover: some may live in an urban area, while others remain at an ancestral site in a rural area. The structure, functions and internal relationships of a family are therefore affected by such mobility patterns (UN, 2005). In South Africa it has been noted that unemployed and/or sick adult children may regroup in their parents' home, with the grandchildren, to be cared for by a grandparent (Moller & Ferreira, 2003). Finally, child headed families, where no adult is present and both parents

have presumably died – typically from an AIDS related illness, are increasingly common (Giese et al., 2003; Lang, 2005).

The effects of AIDS, such as associated illness, or the death of a young father or mother, or both, mean that children may need to be relocated to be cared by other family members elsewhere, in most cases by grandparents, especially a grandmother (WHO, 2002a; UN, 2005). Hence, some families, or households will experience an increase in the number of co-resident young children rendered vulnerable or orphaned by AIDS.

Changes in family structures may alter relationships between family members. In skip-generation households, the generation gap between grandparents and grandchildren may contribute to strained relationships, especially where grandchildren are disobedient and perceived to be disrespectful (HAI, 2003a; HAI, 2005b). Several trends and factors in the SSA sub-region thus contribute to changes in family structures, and by implication to changes in family relationships. Such changes typically result in a reversal of roles for older persons, as they become care providers, no longer care recipients, which latter role they may indeed have anticipated in old age (WHO, 2002).

1.4.3 The burden of caregiving in older person households affected by HIV and AIDS

The burden of caregiving in households affected by HIV and AIDS in South Africa needs to be investigated and understood in terms of a clear role distinction between the sexes in traditional African society. Historically and traditionally, older women have been caregivers: to a spouse and other household members, but especially to grandchildren when the children's mother is sick or absent. Caregiving roles include cleaning the hut, cooking and general maintenance of the home, and caring for the children, the elderly and the sick. Men in African households have historically and traditionally functioned as sole breadwinners, disciplinarians and family heads (Eden, 1991). Men's relationship to their children has thus tended to be authoritarian and disciplinarian, while women's relationship has been one of caring and nurturing. Clearly, caregiving has been gendered in nature and has been women's responsibility (Ferreira & Kalula, 2009). The roles and responsibilities of women in this regard will be considered from a feminist theoretical perspective in chapter 2.

The nature of caregiving for older women in African society has changed somewhat in the era of HIV and AIDS. Now, older women increasingly take care of adult children with AIDS

related illness, and grandchildren with the disease, or orphaned or rendered vulnerable by it (UNICEF, 2004, 1999; Ferreira et .al 2001; WHO, 2002). The resulting burden of care may indeed be heavy, and negatively influence the health and well-being of older women, and limit opportunities for them for social interaction (WHO, 2002).

In this dissertation "household" is defined as a configuration of persons of two or more generations, typically family members, who co-reside in a dwelling. The definition recognises that the household occupies a particular space (a physical structure, or dwelling), and household members share resources. In SSA countries, as has been noted, household configurations are increasingly reshaped by the effects of various demographic trends and social and economic change, especially effects of HIV and AIDS and migration of younger kin. Moreover, older women in affected households increasingly become primary care providers as a result of these changes. As primary carers, they carry the burden of responsibility and care, which is multifaceted. Not only do they care for PLWHA and grandchildren, but must cope with their own deteriorating health, often exacerbated by the stress of caregiving and responsibility (HAI, 2002b). Older persons commonly suffer from chronic disorders such as hypertension, musculoskeletal conditions, respiratory illness and mental health disorders (Ferreira et al., 2001; Akintola, 2004; Joubert & Bradshaw, 2004). Numerous older persons have limited knowledge about the HI virus and its transmission (WHO, 2002a; HAI, 2005c), which then puts them at risk of infection with the virus (WHO, 2002a).

The burden of care has direct and indirect costs on older carers. Direct costs include financial, material and time costs, increased expenditure needs, food insecurity, poverty, health costs and psychological costs. Indirect costs include changing roles, social isolation and stigma, emotional suffering and grief (Johnson et al., 2002; Ogden et al., 2004; Hansen, 1994 in Ogden et al., 2004; Sauerborn et al., 1996; Bachman & Booysen, 2003). An assessment of the financial needs of the caregivers will be undertaken.

1.5 A PUBLIC HEALTH RESPONSE TO SUPPORT OLDER CARERS

By definition, public health is not about individual patients but focuses on disease, and health conditions and problems affecting people collectively, or the public. Thus, public health care

aims to provide maximum health benefits to the largest number of people. A public health approach to a health problem is interdisciplinary, intersectoral and science-based. It draws upon knowledge from multiple disciplines, including Medicine, Epidemiology, Criminology, Sociology, Psychology, Education and Economics (Mercy, 1993; WHO, 2004b). Its interdisciplinarity has enabled the public health field to be innovative and responsive to a wide range of illnesses, injuries, diseases conditions, such as HIV and AIDS epidemics.

Since 1994, the South African government has adopted Primary Health Care (PHC), i.e. health care provided at the primary level in a three tiered health care system, as a vehicle to deliver public health care services. It has used the District Health System as an implementation strategy to ensure that health services are accessible and responsive to the needs of various communities (Pillay et al., 1998). The need to address AIDS has been declared a public health priority and is a Presidential Lead Project (Abdool-Karim, 1995). Among the principles that PHC promotes is a multisectoral approach, or intersectoral collaboration (ISC) to address community and family health care needs (WHO, 1978). Given the multifaceted and complex (health, psychological, social, economic, and developmental) issues presented by the HIV and AIDS epidemic, Primary Health Care, with its comprehensive and intersectoral approach to addressing health problems and the well-being of communities, may be the most appropriate intervention to address challenges faced by households affected by HIV and AIDS (UNAIDS, 2002; WHO, 2002).

Intersectoral collaboration is a process of interaction in which two or more parties identify mutual interests and agree to work together towards a common goal (Challis et al., 1994). The term ISC is used to refer to collaboration between government departments. However, within a PHC context it entails collaboration between government, business, communities and other significant role players in society, to link health care provision to other aspects of socio-economic development that are closely related to health (Pillay et al., 2001; WHO, 2004b). The PHC approach has not been applied in South Africa at the district level to address the multiple problems presented by HIV and AIDS to older person headed households.

A critical element of ISC is intersectoral action. Government, business and strong community participation are essential to all aspects of a comprehensive approach to HIV and AIDS: prevention, care, support and research (World Health Organization, 2004c). UNAIDS has established GIPA, the Greater Involvement of People with HIV and AIDS and their families

(UNAIDS, 1999), which among other activities advocates the promotion and involvement in national responses of people affected by the epidemic such as older caregivers.

Bringing together affected persons and communities in a comprehensive care approach to health problems needs well thought-out models. How, for example, may older persons be equipped and involved in anti-HIV and AIDS strategies? The success of involving older persons in efforts to control or manage HIV and AIDS may have important implications for the broader public health agenda. Indeed, the need for community involvement in the roll out of anti-retroviral therapy, counselling, supervision, monitoring treatment of side effects and support represents an opportunity to build skills and catalyse collaboration between communities, health care providers and public health work, and to help strengthen health systems across the board (WHO, 2002; WHO, 2004c). Research literature on older persons' role in mitigating the effects of HIV and AIDS in countries such as Zimbabwe, Botswana and Mozambique, and on health care support and the empowerment of older women in AIDS prevention in Botswana, found that when previously marginalised grandmothers were provided with knowledge and skills, they became an important and effective resource in the prevention of the spread of the disease and mitigation of its effects (Tlou, 1996; HAI, 2003a; WHO, 2002; Aubel, 2005).

1.5.1 Models to involve older persons in health care service delivery

Although not widely recognised, older persons already play an important role in the "continuum of care strategy" promoted by WHO to address HIV and AIDS at all levels of care (PAHO/WHO, 2000, CEDA, n.d). The strategy involves caregiving at home and in the community, and care at primary, secondary and tertiary levels. Each care level is a service point on a continuum of care for PLWHA and together the points constitute a comprehensive care network. Older caregivers are a vital link in the referral chain between hospitals, clinics, NPOs, CBOs, FBOs and households, where PLWHA are ultimately cared for 24 hours a day, seven days a week. In some developing countries in Africa, Asia and South America, models to involve older persons in the delivery of health services at district level have been tested and applied successfully. The generic grandmother-inclusive methodology model, for example, has five key steps: i) Rapid assessment of grandmothers' role and influence in the household and community related to the issues of interest; ii) public recognition of grandmothers' role in promoting health and development of families and communities; iii)

participatory communication/education activities that engage grandmother networks first, and other community members, second, in discussion of both traditional and modern practices; iv) strengthening the capacity of grandmothers, in families and in the community; and v) ongoing monitoring and documentation for learning (World Bank, 2006; HAI, 2006a).

When this methodology was assessed in both Africa (Senegal) and Asia (Laos), it was found that older persons, including illiterates, are capable of learning new things when the pedagogical approach used is based on respect and dialogue. Hence, older persons are open to combining "new" practices with "old" ones, even when this means abandoning certain traditions (World Bank, 2006). Furthermore, the proportion of older persons who advised mothers with young children to continue breastfeeding during diarrhoea increased from 73 per cent at baseline to 90 per cent at endline (Aubel et al., 1997). In South America (La Paz), older persons were trained in monitoring the implementation of free health care for older people with no health insurance. The results were improved services such as reduced waiting times for older persons at local clinics and the assignment of medical staff with training in older persons' health issues (HAI, 2006b). In a nutrition education project in Senegal, improvements were noted in all indicators relating to grandmothers' advice to younger women and to their own practices with young children (Aubel et al., 2004).

Such evidence and experiences illustrate how government PHC programme developers and planners can put PHC principles into practice, such as community involvement in the delivery of health services in the community and to families. Older persons thus are an important and readily available resource in most communities hard hit by the HIV and AIDS epidemic in South Africa. However, they need support in a number of areas, one being to ensure access to health care – in order to prolong and improve their quality of life, and sustain their contributions, and enable them to participate meaningfully in training and development programmes. Older persons have a right to participate in health care delivery within the district in which they reside. The district health system makes provision for community participation through clinic or community health centre committees (Pillay et al., 1998). Clinic committees are thus a mechanism through which older persons can be drawn into mainstream PHC delivery.

1.6 A RATIONALE FOR THE STUDY

A rationale for the study of older carers' support needs is outlined in three parts: 1) The relevance of the study to society, in terms of the evidence it will yield of the central and crucial role played by older persons in SSA countries and South Africa in the care management of the HIV and AIDS epidemics, and a need to support older carers and their households comprehensively. 2) The relevance of the study to the PHC system, in terms of argumentation in the dissertation for co-ordinated responses to older carers' situations and needs at a district level. The study will have relevance for public health care delivery at community and household levels, as well as for appropriate policy development and implementation. 3) The relevance of the study outcomes in terms of the contribution it will make to knowledge and methodology in the subject area. The parts are elaborated below.

1.6.1 Relevance to society

The relevance of the study to society is two fold: 1) International bodies such as UNAIDS and WHO that work to mitigate the effects of HIV and AIDS tend to focus on people of reproductive age (15-49 years), and children rendered vulnerable or orphaned (OVC) by AIDS. Although older persons are increasingly at risk of infection with the HI virus, they are not targeted in anti-AIDS campaigns, nor do they enter routine surveillance systems, and are neither included in national prevalence estimates, based on ante-natal clinic (ANC) estimates (UNICEF & USAIDS, 2002; HAI, 2005c; Shisana et al., 2005). 2) Although some recognition has been given to older persons' role as care providers to PLWHA and OVC (UN, 2002; UNAIDS, 2004b), they remain unsupported and have largely been overlooked in AIDS policy and programmatic responses (HAI, 2005c).

This dissertation will seek to contribute to knowledge on the complex effects of the epidemics on older caregivers and their households, within SSA settings, and the contributions they make to mitigate the effects and sustain the well-being of their family and community. The study will yield empirical evidence to promote and inform dialogue among relevant role players, including governments. A policy framework will be developed within the dissertation to guide decision makers and other stakeholders in the design and implementation of responses to the caregivers' support needs, to sustain their contributions to family, community and society.

1.6.2 Relevance to public health care

No public health care responses to the HIV and AIDS epidemic in South Africa support affected or infected older persons specifically, despite growing evidence of their being at the forefront of the management of effects of the epidemics at a household level (Ferreira et al., 2001; Bachman & Booysen, 2002; Makiwane et al., 2004). The relevance of the study and dissertation to PHC delivery will lie mainly in the understanding it will provide of the circumstances under which older persons care for PLWHA and OVC. The information the study engenders will be available to inform decision makers, and programme planners and providers on how to respond appropriately to older carers' support needs and a need to protect themselves against infection with the virus at a district level. The empirical evidence the study generates will inform the development of a policy framework to guide PHC, or district management in the design and implementation of appropriate policy and programmes. Recommendations of the study will offer guidelines additionally on how older caregivers may be recruited, trained, supported and integrated into a broad PHC response.

It will be argued in the dissertation that access barriers to PHC experienced by older caregivers must be removed, and public health strategies should help older carers – and their charges – to cope with the burden of care by sustaining or improving the health of the primary caregivers (UN, 2004c). Strengthening intergenerational solidarity and well-being should be central in enabling affected families to cope, and minimising the burden on the over-stretched PHC system (Horizons, 2006). Hence, the relevance the dissertation for public health care will lie chiefly in the information that it provides to inform the development of a policy framework for employment at a district level, which may help to facilitate and co-ordinate the activities of government officials and various other role players in supporting affected older persons' households. The information will serve moreover to inform health care and HIV and AIDS policy processes of older persons' health care needs in general.

1.6.3 Relevance to research methodology

The study will contribute to knowledge in the problem area, specifically through the research design and the research methods employed in the empirical study; in turn, the study will contribute to the design of innovative research approaches and research methodology for other investigations in this subject area. Specifically, and innovatively, the study will i) use a mixed-methods design; ii) gather both qualitative and quantitative data – through a field

survey, follow-up in-depth interviews and case studies, and interviews with key informants; and iii) triangulate (Poundstone et al., 2004; Green et al., 1989) results of analyses of the multiple data sets. The majority of studies in the subject area to date have been of a qualitative type, small-scale and conducted in single settings, thus limiting comparisons between settings and capture of the magnitude of the problem of HIV and AIDS caregiving.

1.7 OBJECTIVES OF THE STUDY

Against the above background and the rationale outlined for the study, objectives of the study are stated as follows**:**

i) To determine the nature and burden of care on older caregivers in households affected by HIV/AIDS in three provinces of South Africa;

ii) To identify the financial, physical, social, emotional and health care needs of older caregivers, and factors facilitating and hindering caregiving in urban and non-urban areas of the provinces;

iii) To assess the caregivers' knowledge of HIV/AIDS;

iv) To review and evaluate current policy responses to the support needs of older persons affected by HIV/AIDS;

v) To assess how various role players at the district level can support older person households affected by HIV/AIDS;

vi) To provide evidence for policy makers and planners, to inform the design and implementation of appropriate policies, strategies and programmes;

vii) To develop a policy framework to forge collaboration among role players at a district level;

viii) To develop (potential) indicators to measure and monitor the implementation and achievement of key areas of the framework;

ix) To make recommendations for policy, programme review and reform, or new policy development and programme design, and implementation, for district management regarding the support needs of older persons in households affected by HIV/AIDS.

1.8 RESEARCHER'S POSITIONALITY

The researcher's positionality in the study is as follows: Prior to the study, he was employed at the Human Sciences Research Council (HSRC), where he gained considerable experience in research problem formulation, research methodology, and the management of research data and the dissemination of research outcomes, as well as conducting research on HIV and AIDS affected populations. Prior to working at the HSRC, he was employed as a researcher and development worker in low socio-economic communities in the Western Cape Province. During the study, the researcher left the employ of the HSRC and since then has been employed as a senior researcher in the Institute of Ageing in Africa at the University of Cape Town. The researcher has therefore worked extensively in a research environment, and latterly specifically in the areas of ageing, older persons, HIV and AIDS, and health and social care. Field notes kept by him from projects conducted in these areas over the years provided him with a rich source of information regarding older persons and caregiving in general. These notes would be helpful to form a broad picture of the context of the carers' situations, and to elaborate on analysis of the qualitative data to be collected and in writing up the dissertation. Moreover, his linguistic and cultural commonality, and first-hand observation of older carers in the study population enabled him to seek to understand older carers' situations acutely and sensitively.

The researcher's involvement in the dissertation and study will entail the conceptualisation of the study; a review or related literature and policy; the development of tools to gather data (i.e. a survey questionnaire, case study and key informant interview schedules, information/consent forms and resource pamphlets); recruitment and training of fieldworkers and field supervisors in each province; management of the fieldwork; negotiation with participating NPOs and community leaders to gain access to the study sites and participants; conducting of qualitative studies; capture of the data; statistical and content analysis, and triangulation of different datasets; interpretation of the results; and the construction of a policy framework.

1.9 OUTLINE OF THE DISSERTATION

The dissertation is organised in seven chapters as follows**:**

Chapter 1 gives background, and states the problem for investigation and a rationale for the study. An argument is made out that while older carers contribute substantially to the care management of the HIV and AIDS epidemics in sub-Saharan Africa, their contributions and capacity need to be integrated in mainstream responses to effects of the epidemics, and the carers need to be supported, in this case at the district level.

Chapter 2 reviews literature on the effects of HIV and AIDS on older persons; the contributions that older carers make to mitigate the effects and the challenges they face; and the epidemics as a public health problem. Issues examined include problems relating to orphanhood – due to AIDS mortality, such as psychological development, schooling and health of OVC, challenges posed by stigma and discrimination associated with HIV and AIDS directed at older persons, and related stress and difficulties associated with caregiving.

Chapter 3 reviews international instruments and relevant national policies, strategies and programmes and community responses, in terms of their inclusiveness and responsiveness to the support needs of older persons affected by HIV and AIDS. Policies, programmes and legislation in South Africa in this regard are examined specifically. Community based care models and programmes within a PHC context are evaluated to assess their supportiveness of affected older person households. Gaps in policy are identified, as is a need for a policy framework for the development and implementation of appropriate responses within a PHC system elaborated.

Chapter 4 describes the research design employed in the study: a mixed-methods design that incorporates quantitative and qualitative techniques – specifically, a field survey, follow-up unstructured (qualitative) interviews (case studies), and interviews with key informants. Planned triangulation of the results of analyses of the several datasets is described.

Chapter 5 presents the results of analyses of the survey data, the unstructured interview data and the case studies, and the key informant interview data, in three parts. The results of the analyses are then triangulated in a fourth part, and the study findings discussed broadly.

Chapter 6 develops a policy framework for decision makers and other stakeholders, for employment to inform policy and programmatic review and reform, towards the provision of support of older caregivers at the district level. The chapter draws on the outcomes of the literature and policy reviews in Chapters 2 and 3, and the results of the survey and triangulation of the findings in Chapter 5. The framework elaborates nine key desired outcomes to be accomplished to meet the support needs of older caregivers, and benefit older persons in general, at the district level.

Chapter 7 draws conclusions of the dissertation, evaluates the study and dissertation, and makes recommendations for strengthened policy and programmatic responses to older carers' support needs in sub-Saharan Africa and South Africa specifically.

CHAPTER TWO: REVIEW OF THE RELEVANT LITERATURE

2.1 INTRODUCTION AND BACKGROUND

Literature relevant to the problem for investigation is reviewed in chapter 2. The chapter is divided in four parts: Part A examines the situation of older persons who become carers to persons living with HIV and AIDS (PLWHA) and orphaned and vulnerable children (OVC) in sub-Saharan African (SSA) and South African settings. Part B examines informal caregiving at the household level and the nature and challenges of the caregiving. Part C examines non-formal care provided by non-profit service organisations (NPOs). Part D investigates formal care provided by the government through social security and health care services, and considers opportunities for Primary Health Care (PHC) to render support to older carers, which include integrating them in service and intervention programmes at a district level; harnessing their energy, skills and other resources; and supporting the carers in order to sustain their contributions to the care management of the epidemic. The state of knowledge in the subject area, as embodied in the literature, is evaluated throughout the chapter. Gaps in knowledge are identified at the end of the chapter.

Theoretical perspectives employed in the dissertation are outlined briefly in Section 2.2 first.

2.2 THEORETICAL PERSPECTIVES

Several theoretical perspectives were considered as being appropriate for employment in the dissertation, among which were Family stress theory (Hill, 1949), Marxist theory (Curtis, 1996) and Development theory (Kasternbaum, 1993). However, two other theoretical approaches were selected for this purpose: Social exchange theory and Feminist theory. The theoretical perspectives are employed in the dissertation to develop analytical and explanatory frameworks, as a lens through which to examine and understand caregiving by older persons at the household level.

2.2.1 Social exchange theory

Social exchange theory was developed by George Homans (1958) who employed it to study and explain motivations for behaviour relating to reciprocity: specifically, the balance and structure of social exchanges in micro-economic undertakings. Social exchange theory differs

from classical micro-economic theory in that long-term relationships are of interest, whereas micro-economic theories were developed on an assumption that exchanges take place between people who do not know one another (Molm, 2001). Social exchange theory can be applied in a range of disciplines, but in all instances the driving force is that of actors exchanging resources – tangible and non-tangible – through or within a social relationship (Homans, 1961). Between household members, for example, tasks become exchangeable resources, as do financial arrangements, or wealth flow patterns. The theory attempts to account thus for exchange behaviour between individuals, or within dyads (Emerson, 1976; Bumagin & Hirn, 2001). Such behaviour may differ between individuals of different ages, because of shifts in roles, skills and resources over time and that accompany ageing.

The relevance of the theory for the construction of an analytical and explanatory framework in the dissertation is as follows**.** Exchanges between actors within households (i.e. caregivers, PLWHA and OVC) are both tangible (monetary, food, shelter, etc.) and non-tangible (co-operation; availability, respect, companionship, etc.). The PLWHA and OVC may therefore co-operate and/or show respect, for example, to an older caregiver in return for care (accommodation, food, clothing, money, medication, emotional comfort, etc.). However, exchanges between actors may not be equal, and may result in one actor (e.g. a. caregiver with more resources than the person being cared for) being "in control of" the exchange relationship. Exchange theorists equate such control with power, since the caregiver will have more to give than the care recipient – at that stage. Although there is an element of reciprocity between the actors, older persons tend not to put an emphasis on reciprocity, especially when the beneficiary of the resources is a family member (Stoller, 1985). Reciprocity may indeed be postponed until such time as the carer is him-/herself in need of care. With advancing age, older persons may depend increasingly on their children, and to some extent on their grandchildren – for whom they cared – for support.

It is accepted that numerous older persons provide critical support to their children and grandchildren (Walker, Martins & Jones, 1992), especially in multi-generational households affected by HIV and AIDS. In such households there will be gains and losses in social exchanges for older caregivers – because of the nature of the effects of HIV and AIDS and the demands of caregiving. Hence, while PLWHA and OVC will benefit from an older person's caregiving, the older person him-/herself may forego privacy, energy, social contact

and income generating opportunities, and the carer's health may deteriorate; losses therefore outweigh gains. The older caregiver is likely moreover to experience stress due to a variety of factors, such as overcrowding of the dwelling, onerous caregiving responsibilities, and concern and anxiety (Bumagin & Hirn, 2001; Kyobutungi, et al., 2009; Mckenry & Price, 1994). Pulloni and Lee (1992: 82) view the foregoing factors, or conditions as the "bottom of the iceberg," since they start long before the death of the PLWHA. The ailments may worsen, in cases for example where the PLWHA played an essential or valuable role in the household, such as earning income, and/or helping maintain order and discipline among household members.

Older caregivers by definition assume the role of caregiving at an advanced age, and some may be needy and/or disabled. Despite frailties, the evidence shows that they nonetheless want to protect and care for their offspring, whom they view as their responsibility, do not see any alternative than to care for them themselves (Bumagin & Hirn, 2001). In better times the carers would provide care, when needed, on an implicit, traditional assumption that they will be cared for reciprocally when they need care (Blau, 1964; Kelley, & Thibaut, 1959; Thibaut & Kelly, 1978). In the case of HIV and AIDS, however, the death of a PLWHA is a distinct possibility (or indeed a probability), and no future reciprocity can be expected. An older caregiver may nevertheless anticipate reciprocal care and companionship from grandchildren for whom he/she cares, when he/she is very old and possibly frail, and in need of care. Hence, caregiving may be viewed within a social exchange theory framework as an undertaking involving both material or tangible and non-tangible emotional transactions in social exchanges, but a notion of equitable reciprocity may be variable (Bumagin & Hirn, 2001). In such cases, social exchange theory may no longer be applicable

2.2.2 Feminist theory

Feminist theory offers a view of events, practices, attitudes and behaviour as a collective process of discrimination against women. It is a political discourse aimed at equal rights and legal protection for women. The collective feminist theories are concerned with issues of gender differences, and advocate equality for women, protection of their rights and interests, and prevention of their exploitation. The theories argue, for instance, that women's work such as caregiving is allocated a lower social status and is regarded as unpaid labour (Canfield, 1997; Humm, 1990; Michael, 2007).

Indeed, feminist theorists argue that gender should be a primary consideration in understanding ageing and older persons because women make up the majority of older adults, and because older women are disproportionately affected by poverty and chronic illness. In addition, community-based, long-term care of older adults depends largely on female caregivers' labour: the women are unpaid or underpaid (e.g. nurse aides, community health workers, personal aides), and are often "invisible" (Browne, 1994, 1995, 1998; Calasanti, 1999). The demands of care provision can have negative consequences for women in old age. Key concepts of the theories are gender stratification and power structures, social networks, identity, discrimination, stereotyping and sexual objectification of women (Chodorow, 1989; Lerman, 1990; Ferreira, 1999).

Feminist theories thus promote female attributes and abilities in general. A feminist theoretical perspective is relevant to the dissertation in several regards: 1) It can provide for an understanding of the nature of gender inequalities in HIV and AIDS affected households; 2) it may be used to examine older women's social and lived experiences in the era of HIV and AIDS, and 3) it can help to understand disparities, or deep gender divides in patriarchal African society.

However, the exposition of feminist theory above has been criticised for being Western oriented, which narrows the topic of feminism to purely a struggle between men and women for equality in all spheres of life (Canfield, 1997; Chodorow, 1989/91). Feminists in the developing world view women's situation not only as the result of unequal gender relations, but as a consequence of a wide range of oppressive situations that transcend gender categories, and are related to race, class and citizenship (Uma, 1997; Meyers, 2000; Mohaty, 2003; Davis, 2004). In sub-Saharan Africa, for example, a greater number of women, especially older women, than men head their household, and care for sick children: without resources such as land, education, opportunities for employment and health care. As a result, they may experience particular stresses and have particular support needs. Some authors argue for a need to explore household headship in AIDS affected households, as a demographic variable to help clarify matters relating to household composition and structure (Merli & Palloni, 2004; Ferreira, 2004).

Feminist theories lend themselves eminently moreover to employment in conjunction with social exchange theory. Thus, a theoretical analytical and explanatory framework drawing on

both theoretical traditions for this dissertation will contribute to achieving a deeper understanding of the older caregivers' situations.

PART A: SITUATIONAL ANALYSIS

2.3. THE SITUATION OF OLDER CARERS IN SUB-SAHARAN AFRICA AND SOUTH AFRICA

The situation of older persons affected by the HIV and AIDS epidemics in sub-Saharan Africa (SSA) has been investigated fairly extensively, but mainly through small-scale studies in specific settings. Effects of the epidemics have been found to impact affected older persons lives in multiple ways. International agencies monitoring the spread of the disease show that the SSA sub-region is worst affected by the pandemic globally (UNAIDS, 2004a; 2006; WHO, 2002a; HAI, 2003a). Understanding the situation, concerns and challenges of affected older persons in the sub-region, specifically in South Africa, and in relation to caregiving in particular, calls for expanded knowledge in relevant areas (Knodel et al., 2002; HAI, 2003a; Nusberg, 2006).

Several sub-Saharan African countries are among the world's poorest countries. The countries have limited state resources, and are hampered in their ability to provide infrastructure required to support significant intervention in the lives of citizens infected with and affected by AIDS (Callaghy, 1993; Therkildsen & Semboja, 1995; Clapham, 1996). The absence of a well developed public health service in many of the affected countries means that the burden of caring for PLWHA and supporting OVC falls primarily on the family, and increasingly on older female members, as numerous younger family members, traditionally care providers, succumb to the disease (Barnett & Blaikie, 1992; HAI, 2003a; Knodel et al., 2002; WHO, 2002; Maher, 2006). However, as argued by feminist theorists, caregiving to PLWHA and OVC is overwhelmingly a female occupation, is assigned a lower status and is acknowledged as a sub-stratum of women's unpaid labour (Canfield, 1997). Consequently, caregiving is viewed as "unimportant" activity and not contributing to the country's overall economic development – which may be partial reasons why older caregivers are not supported by the state.

In most sub-Saharan African countries hospitals tend to be concentrated in urban centres, far from rural areas where the majority of older persons live, and who have difficulty in paying for transport to reach a health centre and obtain health services (Joubert & Bradshaw, 2001; HAI, 2003b; Mwape, 2003; International AIDS Alliance, 2003; WHO, 2002; Akintola, 2004). Although health policy in some SSA countries, including South Africa, exempts the payment of fees for health care for children younger than six years and social pensioners at primary level, the policy is often not implemented at the facilities (HAIKenya, 2001; HAI Kenya, 2003; HAI, 2004a; HAI, 2002-2005).

Older clients' health needs are often marginalised in health care services (United Nations, 2007a), which renders them vulnerable as a group. The burden of HIV and AIDS related caregiving worsens their already difficult socio-economic situation and general wellbeing. Numerous older carers suffer financial, emotional, physical and sexual abuse by PLWHA. Many older carers are unemployed, through age discrimination employment policies or because of caregiving responsibilities. Certainly, caregiving by older persons comes at a great cost to them on a number of levels, since they become virtually isolated from opportunities that could help them replenish losses they incur through caregiving. Social exchange theorists view such a situation as an unreciprocated transaction since the carer receives no benefits for the efforts he/she puts into caregiving. Worst of it all is that some female carers are accused of witchcraft and suffer dire consequences of the allegations, such as having to flee their home and area, and even be at risk of being killed (Forrester-Kibunga, 1999; Forrester-Kibunga & Dianga, 2000**;** James, 2004; Fouad, 2004; Noumbissi, 2004; Niehaus, 2001; Hoffman, 2004; Ferreira, 2004; WHO, 2002).

2.4 CROSS-CUTTING ISSUES IN CAREGIVING RELATING TO HIV AND AIDS

Several studies have identified issues relating to caregiving rendered by older persons to PLWHA and OVC due to HIV and AIDS in the sub-region (Ankrah, 1993; Ferreira et al., 2001; HAI, 2002a, 2004; International HIV/AIDS Alliance, 2003; Mwape, 2003; WHO, 2002a). The majority of the studies have described the burden of care, and the multiple and complex responsibilities that older caregivers carry and tasks they perform, as well as the contributions they make overall. Among the issues are chronic poverty, specific challenges in rural and urban settings, gender related factors, human rights issues, unsatisfactory living

arrangements; social security problems; stigma and discrimination (HAI, 2003b; HAI-Kenya, 2002; Heslop & Gorman, 2002; Makiwane et al., 2004; Schatz & Ogunmefun, 2005; WHO, 2002a; K'Oyugi & Muita, 2002). The issues are elaborated below.

2.4.1 Poverty and caregiving

In sub-Saharan Africa, older people are among the poorest of the poor, and effects of HIV and AIDS worsen their economic situation further (Barnett & Whiteside, 2002; Booysen, 2002; HAI, 2003a; Steinberg et al., 2002). Given the protracted period of morbidity before a PLWHA succumbs to the disease – or in Barnett's classification, a "long-wave disaster" (Barnett & Blaikie, 1992), older caregivers are often left physically exhausted, and indebted through expenses relating to AIDS treatments and subsequent costly funerals (Barnett & Blaikie, 1992; Deininger et al., 2001; Schatz & Ogunmefun, 2005). The responsibility for meeting such debts invariably falls on an older caregiver. Older person headed households affected by AIDS in SSA countries typically find themselves in a downward economic spiral (HAI, 2003a, 2005; Akintola, 2004).

Chronic poverty compromises older carers' ability to care adequately for themselves, PLWHA and orphaned children left behind. They experience difficulty in obtaining sufficient food, clothes and shelter, and paying for health care, and have limited access to education services and transport (Ferreira et al., 2001; HAI, 2003a; Heslop & Gorman, 2002; Maher, 2006). A survey of AIDS affected households in northern Uganda found that for 65 per cent of households in which an adult aged 20-39 years had died, the most grave consequence of the death was the household's "financial ruin." (Ayiga et al., 1999). This characterisation of such households was slightly higher than for cases where the death was due to a cause other than AIDS (Ayiga et al., 1999 in Knodel et al., 2002; Ngalula et al., 2001). Indeed, the loss of remittances from a deceased breadwinner as a result of AIDS in a household, who in most cases worked and earned income in an urban area, may be expected to affect the standard of living of both the older carer and the household (Knodel et al., 2002; WHO, 2002a; Akintola, 2004; Kimuna, 2004; Hosegood et al., 2007). As devastating as the disease is, the HIV and AIDS epidemics in SSA have opened a window of opportunity to challenge and address the gendered nature of caregiving and inequalities between males and females in the region. The non-remuneration of caregiving, from a feminist perspective, is an indication of a patriarchal society which fails to value women's contribution within the home environment. To attest to

the costly nature of caregiving for the actors, a study conducted by the Kaiser Foundation in South Africa found that 66 per cent of affected households had lost their main source of income due to HIV and AIDS related morbidity or mortality, and almost half reported having insufficient food (Steinberg et al., 2002). A study of older caregivers in Khayelitsha, a highly affected suburb in the Western Cape, found that all households cited financial difficulties as the most serious problem they had to deal with (Ferreira et al., 2001). While half the respondents received a social pension, the other half were younger than 60 years and not eligible for pension benefits. The carers related their difficulties to "poverty" and "no income." Poverty is even more stark among older caregivers in rural areas (Barnett & Whiteside, 2002; Williams, 2003). Being old, they have limited opportunity for income generation; live in poor housing with inadequate security; are often isolated and have difficulty in accessing support resources; are unable to work their fields, and sow and harvest crops – because able-bodied kin have migrated or died; and face the consequences of droughts, pestilence, theft of livestock and poor health (Barnett & Blaikie, 1992; Barnett & Whiteside, 2002; HAI, 2003b).

2.4.2 Caregiving in urban areas and rural areas

Hence, challenges of caregiving faced by older carers who reside in urban areas and rural areas may differ. Older carers in rural areas are affected by the rural to urban migration of young, able bodied men and women, who seek job and education opportunities in an urban centre, which apart from a loss of support, results in large numbers of older family members becoming primary carers to young and sometimes disabled children left in their care (HAI, 2001; Tewodros, 2004; HAI, 2005a). In Mozambique, which has a long history of labour migration to South Africa, a study by HelpAge International found that "…migration of young adults results in older persons often looking after grandchildren or other sometimes sick dependants for long periods of time" (HAI, 2003b). Some studies have highlighted the implications of migration of younger kin for older carers. The carers are left behind in a rural area with limited resources, yet have to take care of sick and dying adult kin when they return to their rural home from an urban area (Dayton & Ainsworth, 2002; Knodel & Saengtienchai, 2001).

Rural areas are generally under resourced relative to urban areas, and are typically characterised by poor infrastructure, roads, dams, electricity supply and telecommunication

(Kimuna, 2004). The geographical distance between most urban areas and rural areas in sub-Saharan Africa moreover limits accessibility to support from well resourced urban areas and makes it difficult for urban based kin to send remittances to elderly parents, depriving them of income and complicating caregiving further (HAI, 2004b; HAI, n.d.; WHO, 2002b). Older persons in urban areas are better informed about HIV and AIDS than their counterparts in rural areas **(**HAI, 2004c; BOLD, 2006).

Thus, wide disparities exist in the social and economic conditions of older persons and their households in rural areas and urban areas of sub-Saharan Africa. These disparities are often due to greater investment in towns and cities, which stimulates economic growth and employment opportunities. As a consequence, rural-based young men and women are attracted to urban areas, thereby denying rural areas support and development from young and dynamic inhabitants (Barnet & Blaikie, 1992; Nhongo, 2004; Rees, 1989; Tewodros, 2004). Although an increasing number of older persons in rural areas provide care with limited resources and under difficult conditions, there is no evidence of a corresponding rise in formal support for these caregivers.

Support for older persons in non-urban and urban settings varies. In non-urban areas, older persons depend largely on a traditional kinship support system or network, and help is provided when needed by extended family and members of the surrounding community (Okoye, 2004). In urban areas, older persons may depend on non-profit organisations and municipalities for services, as well as members of their immediate family for assistance with daily needs and activities (Kimuna, 2004). Given disparities between the resource bases of urban areas and non-urban areas, this study will attempt to highlight crucial resource needs and coping mechanisms in the areas, respectively.

Certainly, the disparities are exacerbated by the migration of kin from non-urban to urban areas. In terms of social exchange theory, an older person may be disadvantaged by his/her locality in a non-urban area if no support is forthcoming from urban kin (Emerson, 1976**)**. Hence, a caregiver's support network within a non-urban area and his/her contributions are not reciprocated.

2.4.3 Gender and caregiving

In much of sub-Saharan Africa, women continue to live under strong patriachal influence and are effectively treated as second class citizens (AIDS Law Project, n.d; Schoepf, 1988; Kaleeba, et al., 1991; Standing & Kisekka, 1989; Kimuna, 2004). Many older women lack the right to inherit land and property that could serve as a resource to sustain themselves and those under their care (AIDS Law Project, n.d; Hardy, 1999; Coopoo, 2000; HAI, 2003b/2005a; William & Tamale, 1991). The task of caring for PLWHA generally falls primarily upon women, in congruence with women's traditional roles of caring for the sick and for household members (De Bruyn, 1992; HAI, 2003b; Hoffman, 2004; Okoye, 2004). The assumed gender roles between the sexes certainly serve to perpetuate an imbalance in a power relationship between men and women, such as men being the head of the household and therefore making decisions on the roles that each family member must perform, with women inevitably assigned caregiving as one of their roles.

Some researchers have suggested that AIDS creates a "grandmothers' disease," because of the disproportionate burden of care the epidemic places on them (Beer et al., 1988; Adamchak et al., 1991; WHO, 2002a; Nusberg, 2006). Older women must adjust their daily lives to accommodate new caregiving responsibilities (PANOS, 1990; Ferreira et al., 2001; HAI, 2005; Makiwane et al., 2004). The greater part of caregiving to PLWHA and orphans is indeed provided by older people, and up to 90 per cent of that care is provided by women (UNAIDS/UNPFA/UNIFEM, 2004). Two-thirds of caregivers in surveyed households in southern Africa have been found to be female, almost a quarter aged 60 years and over (UN Secretary-General's Task Force on Women and AIDS, 2004). Hence, female older carers in SSA play a crucial role in the survival and sustainability of AIDS affected families and communities (Burman, 1996; HelpAge, 2003b; Akintola, 2004).

In southern Uganda, Seeley et al. (1993) found more principal and assistant caregivers were women (56 %) than men (44 %). Also in Uganda, Kaleeba et al. (1991) observed that PLWHA whose mothers are still living tend to live longest, whilst those without a female relative survived for a much shorter period. The strain of caregiving on older women is however particularly severe where they live alone and without spousal support: such women are often poorer, depend more on friendship and goodwill, and are less entitled to, or able to access work opportunities than elderly men (Barnett & Blaikie, 1992). In instances where grandparents cannot afford to send all their orphaned grandchildren to school, boys are more

likely than girls to go to school; the education of females has a lower priority in a patriarchy than male education (World Bank, 1993; Sagner, 2000). Indeed, such differential treatment of boys and girls perpetuates a power imbalance between the sexes into old age, with the scales tipped in favour of the boy child.

Some research however, suggests that the notion that men assume less responsibility for caregiving may be a stereotype. A few studies have focused on caregiving by men in the context of HIV and AIDS, and have acknowledged that men play a greater role in this regard than realised (Jackson, 2002; UNAIDS, 2000a). Although caring for PLWHA is thus performed largely by older women, older men also play a role. A few studies have examined shared caregiving by spouses, although some of the studies identified gender based roles within shared caregiving (Horizons, 2004b; Maher, 2006; WHO, 2002a). Older women have been found to provide mainly palliative care to sick persons, including food preparation and feeding, washing and changing bedding, and administering medicine. Older men have been found to provide financial and other types of material support, to run errands, and to make decisions about the care of the PLWHA (HAI, 2002b; Dlamini, 2005; Horizon, 2004; WHO, 2002a). Evidence from South Africa (Steinberg et al., 2002) and Uganda (Akintola, 2004) suggests that some men employ and pay for the services of people to care for their sick relative while they go out to work. It has not been shown, however, to what extent older men are directly involved in the care of PLWHA. The empirical study as a part of this dissertation would therefore not be limited to female older caregivers, but would seek to provide evidence of care roles played and contributions made in such caregiving by older men.

Other types of caregiving rendered by older persons, such as the care of children or grandchildren with a mental disability, are also relevant to this review. Engelhardt, Brubaker and Lutzer (1998) pointed out that parents are able to provide better care for their children if they themselves receive help or support; a subjective assessment of their own ability to provide care for their sick child was significantly related to how much they utilised outside support services, as opposed to the degree of the child's disability or characteristics of the caregiver. Yet other investigators have established that as a caregiver grows older, his or her informal support system weakens and the elder is no longer available to provide services as previously (Heller & Factor, 1993; Akintola, 2004).

2.4.4 Caregiving and human rights

Informal and non-formal caregiving at a micro level and a meso level is encouraged by governments and civil society as a key element in the management of the HIV and AIDS pandemic, especially in a context of inadequate resources (HAI, 2006a). However, informal care is stressful to carers and may be deficient for recipients. Safeguarding the human rights of both PLWHA and older caregivers is therefore an essential component in the effective management of the HIV and AIDS epidemics (HAI, 2003b; UNAIDS, 2004b).

> *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood* (Universal Declaration of Human Rights, 1948, Article 11).

Instruments of international bodies such as the United Nations (UN) provide for the protection and promotion of the rights of older persons. The UN Vienna Plan on Ageing (UN, 1982) gives guidelines in respect of Member States' obligations regarding older persons' rights. The UN Principles for Older Persons (UN, 1991) provides for the protection of their rights to independence, participation, dignity, respect and care. Article 24 of the African Charter on Human and Peoples' Rights states that "All peoples have the right to a general satisfactory environment favourable to their development." Thus, by implication all of these rights are to be enjoyed by PLWHA as well as those affected by HIV and AIDS. The rights are reiterated in the UN Madrid International Plan of Action on Ageing (UN, 2002b). The majority of older persons in sub-Saharan Africa are unaware of the provisions to protect their rights in the international instruments, and hence neither demand nor exercise these rights (UN, 2003; Troisi, 2004).

In South Africa, older persons are sometimes described as one of the most vulnerable sections of the population. Yet, apart of large cash transfers to the older population in the form of the social old age grant, they are consistently overlooked in the allocation of other social resources, such as housing (HAI, 2001). Among rights that the country's constitution guarantees all citizens the right to education and information, the right to access to health care, and the right to not be unfairly discriminated against. Section 29(1) of the constitution states that everyone has the right to be educated (Mbazira, 2006), but the right is violated where older persons are excluded in campaigns to inform and educate citizens on the risks of

HIV infection and caring for a PLWHA (Tewodros, 2004; Maher, 2006; UNAIDS/WHO, 2005).

Globally, persons aged 50 years and over who care for PLWHA and affected children are at risk of infection with the virus, but are invisible insofar as they are omitted in official HIV and AIDS statistics (Jackson, 2002; WHO, 2002a; HAI, 2003b; UNAIDS, 2004). Older caregivers lack information and resources to reduce their susceptibility to infection. Mostly, information on HIV prevention, and counseling, support and care are directed at the section of the population (aged 15-49 years) viewed as sexually active and therefore at greatest risk of infection (Knodel et al., 2001; HAI, 2004c; Maher, 2006). Hence, older persons are not viewed as sexually active nor at risk of infection with the HI virus, and are excluded, or overlooked in programmes.

The systematic exclusion of older persons in data collection, training and services relating to HIV and AIDS moreover removes opportunities for them to obtain information to promote awareness and prevention, and where to access care and treatment for PLWHA (HAI, 2003b) - which situation violates their right to equitable access to services (United Nations, 2001; Tewodros, 2004; Tewodros & Nhongo, 2006:33). Besides, literacy levels among older caregivers in the majority of SSA countries are low, which limits their access to written information that is available. Older caregivers are thus left largely uninformed about HIV and AIDS and how it is spread, which diminishes a perception of their being at risk, and leaves them vulnerable to infection, and unable to protect themselves and those in their care (Knodel et al., 2001; Barnett & Whiteside, 2002; Foster, 2002; HAI, 2003b/2004a; Msimang, 2003). Neither is information on anti-retroviral therapy (ART) targeted at older persons; assumed not to be at risk of infection, they would neither have equitable access to ART if infected. Besides, the majority of infected older persons are only diagnosed with the disease at an advanced stage, when ARV treatment will no longer be effective (Linsk, 1994; Zelenetz & Epstein, 1998; Szirony, 1999; Wooten-Bielski, 1999).

No HIV and AIDS interventions of the South African government make explicit reference to older people as a target group at risk of contracting the virus, even if they are caregivers to PLWHA. Notable is a lack of routine screening for persons aged 50 years and over at routine surveillance sites, such as voluntary counselling and testing centres (VCT), and the non-

inclusion of these persons in national syphilis and HIV prevalence rates reports (DoH, 2003/04/05; HAI, 2006b).

2.4.5 Living arrangements and caregiving

Living arrangements of older persons largely determine the support they enjoy from kin and their well-being. In SSA countries, older persons typically reside in multigenerational households. Co-residence with younger family members is viewed as part of a "lifetime reciprocity" arrangement in which children traditionally help their aged parents in exchange for parental support at various stages in the children's lives (Cowgill, 1986; Cowgill & Holmes, 1972; Albert & Cattell, 1994; Lesthaeghe, 1983; Nhongo, 2004). However, family structures in these countries are changing, away from the extended family structure and system. The urbanisation of young adult kin is one such change trends which impacts traditional kin structures. New family forms are nevertheless evolving, such as nuclear families, mainly in urban areas, but which may no longer guarantee older members the care and support their counterparts enjoyed previously – and may have anticipated receiving in old age. Indeed, in many households affected by AIDS, numerous older members are thrust back into the role of primary caregivers, no longer care recipients (Ferreira et al., 2001; WHO, 2002a; Makhubalo et al., 2004; Maher, 2006).

Skipped-generation households, in which both middle-generation parents are absent – either due to migration, or mortality relating to HIV and AIDS or other conditions, are increasingly common in SSA countries (Barnett & Blaikie, 1992; UN, 2005). Older persons, especially older women, who co-reside with and care for orphans in such households have been found to have a low well-being index (HAI, 2003a; UN, 2005). Neither is their investment in caring for the PLWHA likely to be reciprocated with care, when they are old, from a PLWHA who will eventually die (HAI, 2006a). After the PLWHA dies, older carers may find themselves destitute and without any support (SA-PPA, 1997; Goodwin, 1999; UNAIDS, 2000a; Beresford, 2002; Rehle & Shisana, 2003; UN, 2005). Indeed, given the pressure of caregiving for a household member with a prolonged illness such as AIDS, a carer's partner or spouse may desert her and the household, thus diminishing the household's ability to cope with the effects of the disease even further (Barnett & Blaikie, 1992; Ferreira et al., 2001). The caregiving role performed by older persons may be viewed, or understood not in terms of material tangible reciprocity, but non-tangible benefits (Homans, 1961), since the PLWHA

will inevitably succumb to the disease. The only benefit an older caregiver will gain is satisfaction of having helped a loved one in need. Similarly, filial relationship would be a motivation for the carer to care for OVC, which could be understood as a future investment, to benefit the older carer when he/she needs care due to frailty or ill-health.

2.4.6 Social security and caregiving

The presence of individuals with HIV and AIDS in a household strains already limited resources and the capacity of older members to care for other sick household members, orphans and vulnerable children. The loss of a PLWHA who was a breadwinner severely reduces a household's income (HAI, 2003a). Of SSA countries most affected by HIV and AIDS, only six – Botswana, Lesotho, Mauritius, Namibia, Senegal and South Africa – have a comprehensive social protection programme, typically in the form of a basic non-contributory old age pension (Giese et al., 2003; HAI, 2003b/2006b). In some SSA countries that provide no social security or social assistance for poor older citizens, these persons must rely on family or personal livelihoods for financial support. Several older carers turn to informal, or community based money saving schemes, but which are risky, difficult to manage and unreliable (Chima et al., 2004; Tewodros, 2004).

Of SSA countries that provide a non-contributory social pension, South Africa's programme is unique in its near universality and relative generosity (Ferreira, 1999). Along with that of Brazil, South Africa's programme is the most expansive in the developing world (Barrientos & Lloyd-Sherlock, 2003). In 2008, women aged 60 years and over and men aged 63 years and over were eligible, based on an income and assets means test, to receive a pension, or social grant of R940 a month (Mbola, 2008). Prior to 2008, the age of eligibility for men was 65 years, but parity in the age of eligibility is being phased in progressively; by 2010, all men aged 60 years and over will be eligible for an old age grant (Mbola, 2008). Interestingly, although South African society has historically been patriarchal in its outlook, gender discrimination regarding the pension worked against men and favoured women in terms of age eligibility. Although the old age pension (OAP) is targeted at older persons, studies show that the income is used widely to support entire households (Case & Deaton, 1996; Moller & Sotshongaye, 1996; Ferreira; 1999; Case, 2001; Sogaula et al., 2002; Barrientos & Lloyd-Sherlock, 2003; Moller & Ferreira, 2003; Makiwane et al., 2004). Beneficiaries employ the income to pay or utilities, school fees and transport, and medical expenses, and to buy food and school uniforms for household members. In some cases, beneficiaries share pension

income with family members who live elsewhere (Case, 2001; Giese et al., 2003; HAI, 2004b; Sogaula et al., 2002).

Thus, social pension income provides a regular and reliable source of income to beneficiaries and their households (May, 2003; Giese et al., 2003; Maher, 2006). It serves moreover to protect the health of all household members in households that pool income (Case, 2004; Maher, 2006). In South Africa, female beneficiaries have been found to distribute the income more widely than male beneficiaries (Duflo, 2003). Duflo (2003) found, for example, that young girls' anthropometric status (i.e. weight versus height and height versus age) was significantly improved where female beneficiaries shared pension income with household members, but male beneficiaries' pension income had no significant similar impact on either boys or girls.

Clearly, the OAP is a safety net and a lifeline for many older person headed households, especially in which orphans and vulnerable children reside, and in households otherwise rendered vulnerable and impoverished by HIV and AIDS. Typical expenditure items of female beneficiaries are special nutritious foods, medications and dressings, and transport to take the PLWHA to a clinic or hospital (Maher, 2006).

Notwithstanding the value and benefits of the OAP to beneficiaries and their household, the social grants programme is beset with a number of challenges, among which have been a largely unsatisfactory payment system and non-coverage of all eligible older persons (Barrientos & Lloyd-Sherlock, 2003). Pensions are mainly paid through a contracted third party, the South African Social Security Agency (SASSA), and the monitoring of the pension service delivery is carried out by government (Sapa, 2005). Anecdotal evidence from the mass media indicates that beneficiaries may be robbed at paypoints, or their pension money taken from them by money lenders, or "loan sharks" who wait at the pay points to claim reimbursement of loans (Commision for Gender Equality, 2005; Sapa, 2005). Apart from beneficiary related problems are ongoing challenges of the information technology system, bureaucracy, ineffective administration and fraud by administrators (Sapa, 2005). Literature on the extension of social security, in the form of special grants, to households affects by AIDS in SSA countries is scarce. Very few of the countries indeed provide a social pension to older persons, but is it neither well known whether any assistance is available to vulnerable households. The South African government provides a number of other grants, apart from the

social pension, to categories of eligible beneficiaries, some of which income is used to support OVC. These grants include the child support grant, the foster care grant, the care dependency grant and the disability grant (Giese et al., 2003; Sapa, 2005). Some international studies have found a correlation between household income, including grants, and the well-being of children (Baydar & Brooks-Gunn, 1994; Meyer, 2002; Rawlston, 2000).

All social grants payable in South Africa are means tested, based on an applicant's income and assets. In the case of a social pension, the means test is applied to the income and assets of the couple, if the applicant is married. In the case of most other grants, the total income of a household is taken into account in determining an applicant's eligibility for a grant. The child support grant is designed to target vulnerable children up to 15 years, in 2008, who are living in poverty (Mbola, 2008). The number of children benefiting from the grant increased from 34 471 in 1999 to over 5.5 million in 2005 (Sapa, 2005) – and 8.3 million were estimated to benefit in 2008 (DoSD, 2008). The foster care grant is intended to address the needs of orphans or other vulnerable children, and is intended to target children up to the age of 18 years who have been placed in the care of a foster parent by a court of law. Only foster parents of children placed in their care through a court of law, and not family members of the child, are eligible for this grant (Guthrie, 2000; Children's Institute, 2002; Giese et al., 2003).

The state disability grant, which covers disabled persons – including those disabled by AIDS, has been in existence since the 2001/2002 financial year. Its purpose is to provide financial assistance to persons with a severe disability. However, with respect to AIDS afflicted person, the grant is withdrawn when their condition improves or their CD4 count is above 200 units. In addition, beneficiaries of the grant, and/or their family are supplied with food parcels and supplements, cooked meals, bereavement support and assistance with funerals (Sapa, 2005). However, caregivers to PLWHA who are eligible for the grant experience a number of barriers in accessing the disability grant (Giese et al., 2003; Nattras, 2005; Booysen & van der Berg, 2005).

Barriers to accessing a grant include an inability to provide official documents such as a bar-coded ID and a birth certificate; half of all children in South Africa do not have a birth certificate, and numerous applications for one, in order to apply for a grant, are dogged by extended bureaucratic delays (Children's Institute, 2002; Smart, 2000). Some authors argue that the value of grants, such as the child support grant, is set at too low a level to have a meaningful effect on poverty alleviation in beneficiaries' households (Bredenkamp, 1999;

HAI, 1999a; Sagner, 2000). Children who are HIV positive are legally excluded from eligibility for a care dependency grant unless they have become so ill as to require permanent home care (Giese et al., 2003). The narrow legislated purpose of the care dependency grant, unclear eligibility criteria and cumbersome assessment procedures also add to the grant's inaccessibility (Child Health Policy Institute & The Children's Rights Project, 2000).

An additional challenge for the grant system as well as to beneficiaries is fraud. Citizens who are not *bona fide* beneficiaries apply for and receive a grant. Officials within the Department of Social Development and crime syndicates similarly may defraud the system (Vapi, 2004; Sapa, 2005; Skweyiya, 2007). Hence, a number of bureaucratic barriers and systemic challenges reduce the uptake of grants by people who need such assistance, especially members of households affected by AIDS (Cassiem & Streak, 2001; Children's Institute, 2002; Van der Berg & Bredenkamp, 2002).

2.4.7 Social services provided to older persons

In addition to the old age grant, the state subsidises certain services, provides certain assistance in kind, and subsidises housing in the form of old age homes or frail care facilities for state pension beneficiaries. It does not provide formal housing specifically for older persons who are able to live independently as such; indeed, shelter is increasingly unaffordable to the majority of non-institutionalised poor older persons who depend on the social pension (CGE, 2005). In the majority of African communities the concept of institutional care for older family members is rejected culturally; caring for elders at home is viewed as a kin responsibility (Ekpeyong, 1995; Ohuche & Littrell, 1989). Old age homes neither accommodate grandparents with young grandchildren, which living arrangement many older persons in South Africa prefer (CGE, 2005). Policy has determined that residential care facilities may only accommodate frail older persons in need of 24-hour nursing care, and a small number of socially indigent persons who have no alternative shelter.

In South Africa, old age homes were previously racially segregated and very few homes served the black population. Historically, black older persons, who constitute the majority of the older population, have not resided in such homes; the homes have historically been occupied primarily by whites and coloureds. More recently, a demand for residential care facilities in the black population has been noted. However, the facilities, which by law are now racially integrated, are typically distant from areas where black people have lived historically, and older persons who need shelter are reluctant to relocate to these places

(Ferreira, 2008 personal communication). In sum, black older persons, who as a group are worst affected by the effects of AIDS, have limited access to residential care when they need it.

The state of housing infrastructure, especially shacks and mud homes, in which the majority of older persons in South Africa reside is moreover poor. The houses are typically small and cramped; leak during rainy winter months and swelter in hot summer months; are in need of repair; and lack piped water and flush sanitation - especially in rural areas. Such housing is not conducive to satisfactory caregiving, and in fact exacerbates difficulties associated with caregiving.

2.4.8 Stigma and discrimination of affected households

Older people experience social exclusion generally. However, when PLWHA and OVC co-reside in a household, all members experience social exclusion as a result of stigmatisation of the disease. Social ties and traditional support mechanisms may be weakened when ignorance and stigma marginalise a family affected by HIV and AIDS, leaving them ostracised, isolated and alone, and without the benefit of community support. Goffman (1963) defined stigma as an undesirable, discrediting attribute of an individual that reduces the individual's status in the eyes of society. AIDS is such an attribute – of a household, family or individual – and may result in discrimination experienced by PLWHA and the family, which engenders silence over their HIV status (Dawson et al., 1987; Johnston, 2001). Hence, prejudicial thoughts and behaviours of others, including co-workers, friends, health care providers, government officials, the community and families, regarding AIDS result in the stigmatisation of PLWHA (Cameron, 1993; Jayaraman, 1998; Zierler et al., 2000), and in most cases extend to the family of PLWHA (Jackson, 2002; Procaare, 2001; Nyblade, 2003; Akintola, 2004).

Research shows that HIV and AIDS related stigma manifests itself in multiple ways, including self-isolation, voluntary withdrawal from social interaction and shame (Alonzo & Reynolds, 1995). Some perceptions underlying stigma are that HIV and AIDS is a threat to community values, safety and solidarity (Gilmore & Somerville, 1994). Stigma may therefore extend beyond the PLWHA to the caregiver and other family members. HIV-related stigma

has been particularly difficult to combat, because infected and affected persons sometimes stigmatise themselves through fear, before others stigmatise them. As a consequence, stigma may indeed facilitate the spread of the disease by denying a possibility of infection, discouraging HIV testing and undermining care efforts (Johnston, 2001; Gupta, 2003).

Stigma has been cited as one of the greatest obstacles in combating the HIV and AIDS epidemics (Aggleton, 2000; UNAIDS, 2000d). HIV infection is contagious and deadly, and is often associated with promiscuity and immorality, or perceived as God's punishment to wrongdoers (International HIV/AIDS Alliance, 2003). Moreover, social ties and traditional support mechanisms can be weakened when ignorance and stigma result in the marginalisation of a family affected by HIV and AIDS, leaving the members feeling ashamed and isolated (Anderson & Kaleeba, 1994; Akintola, 2004; Horizons, 2004b; Knodel et al., 2006). As a consequence, many older caregivers are hampered in their efforts to care for PLWHA: they are reluctant to seek help and access resources externally, and feel they are failing in their role as caregivers because they are unable to protect their families from the effects of stigmatisation (HAI, 2003a; International HIV/AIDS Alliance, 2003).

In South Africa and other affected SSA countries, negative and discriminatory attitudes of service providers such as nurses and social workers discourage caregivers from accessing support services (WHO, 2002a; Giese et al., 2003; HAI, 2003b). Media reports in South Africa and research in Uganda indicate that children infected by HIV and those whose parents died of an AIDS related illness are discriminated against, and may not be admitted into some schools because of stigma, as was the case with the late Nkosi Johnson[1] (Sapa, 2002; HAI, 2003b; Simbayi et al., 2006). Interventions to address the epidemic neither include information to help older persons address the epidemic's consequences such as stigma, discrimination and stress in their caring roles (HAI, 2003b).

Highlighting the complex nature of stigma, Jackson (2002) cautions that support provided by governments to households affected by HIV and AIDS, such as those of older caregivers, need to guard against reinforcing stigmatisation and discrimination by targeting "AIDS" household for assistance. Such targeting may result in acute levels of exclusion for older caregivers and OVC living with or related to PLWHA (HAI, 2003b).

[1] The late Nkosi Johnson acquired HIV infection vertically through mother-to-child transmission and became the public face of HIV/AIDS in South Africa until his death in 2002 at the age of 12. He was a keynote speaker in the International AIDS Conference held in Durban South Africa in 2000, when he called for the provision of free anti-retroviral treatment in the public health sector.

Denial of the existence of HIV and AIDS in a family may contribute moreover to the spread of the epidemic (Badade, 1999). Caregivers typically feel a need to hide the condition of the PLWHA out of shame, and to avoid stigmatisation, discrimination and sometimes violence, especially against female carers. Muyinde et al. (1997) found in a Ugandan village that family members of the PLWHA insulate themselves from stigma by denying the presence of the condition in their family. Family members also ensured that the face or body of a deceased AIDS sufferer was not shown to people before burial in order to avoid embarrassing comment in the community. Hence, denial is a barrier to efforts to address the epidemic. The denial of a PLWHA's sero-status by his/her family or caregiver simply encourages the PLWHA to hide the condition and to continue to engage in high-risk behaviour (Qwane, 2001; Strydom, 2000). During the International AIDS Conference held in Durban in 2000, former President Nelson Mandela (2000) urged South Africans to break the silence, avoid denial, banish stigma and discrimination, and ensure inclusivity in the struggle against AIDS. Both stigmatisation and denial of the disease must therefore be eradicated, as they discourage individuals from assessing their personal risk of infecting others (Johnston, 2001; Siegel & Gibson, 1988). The gendered nature of the discrimination and violation of carers, in some cases, is evident in that it is women who suffer AIDS stigma related violence more than men and are hounded from their home and community most (Besley, 2005).

PART B: INFORMAL CAREGVING

2.5 INFORMAL CAREGIVING

Informal caregiving is defined here as care provided by individuals, especially family members, to chronically ill or disabled persons, and other affected and vulnerable persons, within the family, household and community, but not through an agency. Such persons, or care recipients are helped to carry out activities of daily living, such as eating and bathing, and leaving their home to visit a place of worship, to travel to consult a doctor or to take medication such as ART (Takamura & Williams, n.d.).

2.5.1 Care within the family

Traditionally, within African family settings older persons were accorded a place of honour in the lineage of the hierarchy (Nzimande, 1996). The position of honour ensured that they were not forgotten or neglected, or left uncared for by other family members. Traditionally,

moreover, older members relied on younger members for financial and care support (Ekpeyong, 1995; Knodel et al., 2000; Stloukal, 2001). For generations, the practice in Africa of caring for the old by their children was the norm and culturally expected (Okoye, 2004). In turn, older persons had various social obligations that involved, among other, religious guidance, socialisation of the younger generation in self conduct and behaviour, presiding over ceremonies, and the preservation and transmission of cultural and historical information – towards ensuring the well-being of their family and community (Fuglesang, 1982; Akukwe, 1992; Diof, 2000). Traditionally, older persons did not receive "charity" from their family, but existed rather in mutual beneficial supportive relationships with family members, or the clan, which strengthened family and intergenerational cohesion. Therefore, the traditional African family way of life lends itself to examination by employing tenets of social exchange theory. While young relatives may support older relatives financially, the latter will reciprocate by giving guidance and advice, socialising the young, and transferring historical information and other non-tangible but socially valuable information.

However, in the era of HIV and AIDS, roles are often reversed: affected older persons increasingly take responsibility for providing financial support to affected and vulnerable and unemployed family members, caring for the sick, and caring and providing for vulnerable and orphaned grandchildren (Ferreira et al., 2001; WHO, 2002a; Akintola, 2004). Thus, family care patterns are being reversed (Ankrah, 1993; Deininger et al., 2001; Baylies, 2002; Knodel et al., 2002; WHO, 2002c; Maher, 2006). At the same time, older women's capacity to care, especially as they grow older and are burdened with new care responsibilities, diminishes (Knodel et al., 2001; WHO, 2002a; Maher, 2006).

Notwithstanding the enormous burden of care that older carers carry, these informal caregivers are not supported by governments in sub-Saharan African countries, including South Africa (Ferreira et al., 2001; WHO, 2002a; HAI, 2003a; Knodel, 2005). Yet, informal caregiving makes onerous physical, material, psychological and emotional demands on an older carer (Ferreira et al., 2001; WHO, 2002a; Orner, 2006).

2.5.1.1 *Caregiving to orphans and vulnerable children (OVC)*

UNAIDS defines an orphan as a child under 15 years of age who has lost his/her mother (a "maternal orphan") or both parents (a "double orphan") – in this case, to AIDS

(UNICEF/UNAIDS, 1999). In sub-Saharan Africa, in 2006, approximately 9 per cent of children under the age of 15 years had lost their parents to AIDS (UNAIDS, 2006). In South Africa, in the same year, a million children under the age of 18 years were estimated to have been orphaned by the disease (Dorrington et al., 2006).

The large number of so-called AIDS orphans in the sub-region is one of the most serious problems relating to the epidemics (Goodwin, 1999). In South Africa, a survey in four provinces found that 22 per cent of children in households with a PLWHA were maternal orphans (Beresford, 2002). Orphans have been found to suffer a range of challenges, including recurrent psychological trauma – starting with the illness and death of their parents, followed by cycles of poverty, malnutrition, stigma, exploitation and often sexual abuse (Matshalaga & Powell, 2002; Aber & Richter, 2005; Simbayi et al., 2006). The magnitude of the "orphan problem," and the accelerated increase in the number of AIDS orphans in most sub-Saharan African countries earlier resulted in a rush by well-meaning non-government organisations to place orphans in orphanages. However, the response was unsustainable, given the magnitude of the problem and its cost implications, and the small number of orphanages available (Matshalaga & Powell, 2002). It is argued moreover that it is neither in the social, cultural and developmental interests of orphaned children to be institutionalised, and preferable for them to grow up in a family unit (Mwagi, 1994; Ankrah, 1993; UN, 2004b). The fact that most of the so-called "AIDS orphans" are "maternal" orphans points to the gendered nature of the scourge of the disease in South Africa. Again the disproportionate number of deaths of women from the disease suggests that women are at a higher risk of infection than men.

In light of the so-called orphan problem, international agencies and policy makers have come to realise that extended family, with the support of the surrounding community, could provide the most suitable environment for orphans in which to grow up, which is moreover probably the only viable and sustainable solution to the problem (Ankrah, 1993; UN, 2004). In 2001, as part of the UN General Assembly Special Session (UNGASS) on HIV and AIDS, UN Member States committed themselves to meeting the needs of children affected by the pandemic. The declaration emanating from this meeting recognised the importance of care, community support and treatment for an effective AIDS response. Articles 65, 66 and 67 refer specifically to children affected by AIDS (UNGASS, 2001a).

Previously, few international declarations and commitments referred to the role played by older persons in the care management of the epidemics and their value as a care resource. Only in the early 2000s did international instruments such as Madrid International Plan of Action on Ageing (UN, 2002b) and the African Union Policy Framework and Plan of Action on Ageing (AU, 2003) call explicitly for support for older carers; since then, greater recognition has been given to their contribution as carers, but in truth, little action or support have followed.

Fairly extensive literature refers nonetheless to the involvement of older persons in the care of OVC in family settings in sub-Saharan Africa (e.g. Ferreira et al., 2001; WHO, 2002a; HAI, 2003a; Akinsola, 2004; Orner, 2006). It has been widely documented how large numbers of young OVC are cared for at home by a grandparent in his or her fifties or older, and how older persons commonly assume responsibility for the care and support of affected grandchildren (WHO, 2002a; HAI, 2003a). However, the literature refers equally to the real or potential challenges of caregiving to OVC (HAI, 2003a; UN Policy Workshop, 2004).

It is predicted that by 2010 the number of children orphaned by AIDS in SSA will rise to more than 18 million (UNAIDS, 2004a). South Africa ranks second to Nigeria with the largest number of children orphaned by AIDS. An even more interesting ranking of SSA countries is created when the proportion of AIDS orphans is calculated as a proportion of all orphans in each country. The calculations show that South Africa, as well as the majority of its neighbouring countries – Zimbabwe, Botswana and Swaziland, and Uganda in East Africa, are facing a huge problem as children orphaned by AIDS comprise nearly half or more of all orphans nationally (UNAIDS, 2004a; Simbayi et al., 2006).

Research in Mozambique, Uganda and Zimbabwe on health care, support and empowerment of older women who render care to persons infected with or affected by AIDS, such as OVC, found that when the women were provided with knowledge and skills, they became an important and effective resource in the management of the spread of HIV: for example, by educating the children in their care about HIV and AIDS (WHO, 2002a; HAI, 2003a; Akintola, 2004). However, some research has established that when orphaned children are cared for by older relatives, who are unsupported, the children become more vulnerable, and do not attend school, or else schooling is delayed (HAI, 2004b; UNAIDS, 2004b; Simbayi et al., 2006). Caregiving to orphans also creates financial, social, psychosocial and health

related difficulties for the carers. How problematic the difficulties are for a carer will depend on factors such as the carer's age, gender, (previous) occupation, income level, residential location, family circumstances and household type (HAI, 2004a). Older carers with low or no formal education have limited access to written information such as advice on how to protect themselves and OVCs from HIV infection.

2.5.2 Older persons and social capital

Social capital is human resources or capacity available to an individual through family and social ties, upon which to draw as needed. Putnam (2000) provides an inclusive notion of social capital entailing networks and ties, trust and reciprocity and community participation. A community rich in social capital would then be described as a socially cohesive, co-operative and caring community, made up of caring individuals and groups of people who work together for mutual benefit (Onyx & Leonard, 2002; Boneham & Sixsmith, 2006).

Older people provide a vast pool of social capital to their family: as knowledge bearers and educators, and through their roles as caregiver, homemaker and income earner (Gerdes, 1988; HelpAge, 2002b). In most SSA countries, and in South Africa, older persons are advisors to their family and thus able to influence them in HIV and AIDS awareness and prevention (Tewodros, & Nhongo, 2006). Older caregivers moreover provide a sense of continuity and financial support for their grandchildren when their parents have died (Gerdes, 1988; Schatz & Ogunfen, 2005).

At a community level, research has established that most older people are social capital "agents" as advisors to the community, which enables them to influence health related attitudes and behaviour such as breastfeeding practices of young mothers, and HIV and AIDS awareness and prevention campaigns (Onyx & Leonard, 2002; Akintola, 2004; Horizons, 2004b; Tewodros & Nhongo, 2006). In Uganda, Jamil and Muriisa (2004) considered the role of social capital and community responses to AIDS, and argued that Community Home Based Care (CHBC) concerned with fostering social relations between PLWHA, their caregivers and broader communities (as against individualised approaches to HIV and AIDS, such as counseling and testing), has played a crucial role in building social capital in that country. It is crucial therefore that the lived experience of older caregivers supported by CHBC is investigated in terms of how it is influenced by social capital (Knodel, 2005).

Knodel and Saengtienchai (2001) found that older parents in Thailand who had lost an adult child to AIDS reported receiving financial assistance from kin, former employers of the PLWHA and community members to help them to meet funeral related expenses, in addition to assistance with the physical aspect of caregiving. They relied therefore on a social capital network for help and support. The caregivers were consequently able to cope better with the financial burden of AIDS related mortality in their household. In South African communities where the HIV infection rate is high, some people form support groups to co-counsel each other and affected members of their families. A "buddy" system exists in some places moreover whereby individuals infected with the virus are taken in as a friend by someone who is not infected, and encouraged to take their medications on a regular basis; such behaviour is socially approved and encouraged.

Hence, social capital may be viewed as a resource base for social exchanges. Reciprocal exchanges and benefits that occur between actors (older persons, PLWHA, OVC, neighbours, etc.) in communities and households are key elements of these social exchanges. They include social contact, networking, shared costs and social rewards. In effect, the actors (both young and old) act to ensure that the integrity and cohesion of their household remain intact, and household (and community) resources benefit all. Social capital (the network) thus operates at a higher level than the dyadic person-to-person level of social exchange (Emmerson, 1972).

On the other hand strengthening of social networks should not be viewed as a solution for all problems that caregivers face. These networks, which represent social capital, may not be reliable or dependable, and reciprocity could be problematic (Kutz, 2004). In certain contexts, social capital as a source of support may be a "mixed blessing": it may come at a high cost to the individual. Advocates who promote of social networks as a solution to easing the strain of caregiving on older persons should thus be circumspect, and vulnerable caregivers should not be unintentionally exposed to even more stress.

2.5.3 Care and support needs of older persons

Notwithstanding the valuable role that older persons play as caregivers, their personal resources are limited, and the literature has defined a range of areas of concern and need for them. Among these areas is support to enable the carers to sustain their caregiving (Maher, 2006). Recent research has established care and support needs of older caregivers of PLWHA

and OVC in some sub-Saharan countries, including South Africa, from the older carers' perspective (Ferreira et al., 2001; WHO, 2002a; Makiwane et al., 2004; HAI, 2005c; Maher, 2006).

In Zimbabwe, a World Health Organization survey (WHO, 2002a) on AIDS and older people found that nearly two-thirds of caregivers identified finance as their greatest need. Research in Kaloma district in Zambia and Tanzania supported this finding, and established that cash transfers to caregivers prevented their household from sliding into deeper poverty (Department for International Development, UK, 2005; HAI, 2001; Ntozi & Nakayama, 1999). Multi-country studies and consultations conducted by HelpAge International found that although older persons are aware of AIDS, the majority lack accurate information on its causation (HAI Kenya, 2003, 2005c, 2006a). Some studies found that older carers need support with legal matters, such as issues of conflict, property rights and eligibility to social security benefits (Ferreira et al., 2001; Jackson, 2002; Tewodros & Nhongo, 2006; WHO, 2002a). In South Africa, no policy provisions are available for older persons who care for PLWHA and/or OVC, which support is essential if the burden of care on affected older persons is to be addressed.

PART C: NON FORMAL CAREGIVING

2.6 NON-FORMAL CAREGIVING

Non-formal care is defined here as caregiving provided by non-profit organisations (NPOs), such as faith based organisations (FBOs) and community home based care (CHBC) organisations. Non-formal care is delivered through interaction between community support mechanisms and NPOs, often with links to welfare and public health services, and is aimed at meeting the health, physical, psychological, emotional, social and spiritual needs of persons who are sick or disabled (WHO, 2006; UNAIDS, 2004b). This type of care is provided at a meso, or community level, rather than at a household or family level. Non-profit organisations take a variety of forms, depending on the jurisdiction and legal system of a country, and an NPO's goals (HAI, 2003b).

2.6.1 Non-profit organisation (NPO) care initiatives in the community

At a meso level, HIV and AIDS affect the "social body" (Barnett & Blaikie, 1992; Frohlich, 2005): that is, the relationships between affected families and the broader community are impacted negatively by effects of the disease. An example of such impact would be where stigma and discrimination of PLWHA are directed against the family (Jackson, 2002; Procaare, 2001; Nyblade, 2003; Akintola, 2004). Consequently, a main mechanism for managing the epidemics in affected SSA countries has taken the form of co-operation between local communities and non-profit organisations (NPOs), through education, information sharing, counselling, income generation, material support and awareness campaigns (Barnett & Blaikie, 1992; Jackson & Kerkhoven, 1995; Woelk et al., 1997; Wilson, 2000; Jackson, 2002; Steinberg et al., 2002; Horizons, 2003).

In sub-Saharan African countries, community based home care (CBHC) is largely provided by NPOs, sometimes supported by government – which is typically the case in South Africa. Community based home care has emerged as an effective method for delivering non-formal, compassionate care to those infected and affected by HIV and AIDS, such as older caregivers (UNAIDS, 1997; Jackson, 2002; Akintola, 2004; Peltzer et al., 2006). In South Africa, the slow implementation of certain elements of the national response to HIV and AIDS, such as the roll-out of ART, and structural limitations of the public health and welfare systems, have contributed to growing support and care for PLWHA and their families in the community by NPOs (Birdsall & Kelly, 2005; Peltzer et al., 2006). Two NPOs that work closely with older caregivers affected by HIV and AIDS in South Africa are Grandmothers Against Poverty and AIDS (GAPA) and the Muthande Society for the Aged (MUSA). The participation of the non-profit sector in the fight against the disease at the meso level complements the fight at the micro, or household level. Non-profit organisations share their resources (manpower, information on HIV/AIDS, networking, provision of physical space, etc.) freely, in exchange for the co-operation and loyalty of the community they serve, to fulfill a common purpose (Lohman, 1992), such as containing the spread of HIV within a particular community. According to social exchange theory, the NPOs' actions are therefore motivated by a desire to encourage voluntary action for the benefit of all concerned within a community. Most importantly, they aim to enhance affected individuals' quality of life and extend survival for the PLWHA

2.6.2 Interface between NPOs, government and donor agencies

Non-profit organisations rely largely on government and international donor agencies, such as the Global AIDS Fund, ActionAid, the European Union (EU), Oxfam and HelpAge International, for information, material support and funding to sustain their activities, including remuneration of staff (Jackson, 2002; Peltzer et al., n.d.). Non-profit organisations that deliver services on behalf of the government to affected communities experience a number of challenges, however. In South Africa, the organisations experience bottlenecks or delays in the distribution of funds, which impact service delivery negatively (Save the Children, 2006; Phaswana-Mafuya et al., 2008). Research evidence indicates that donor agencies must deal with complex procedures and application forms, and stringent requirements that are often incompatible with an NPO's activities. Most NPOs do not have the capacity to administer large amounts of funding (Jackson, 2002; Save the Children, 2005).

However, research also shows that NPOs are most valuable and effective if they work with, rather than parallel to, governments (UNAIDS, 2004b; Phaswana-Mafuya et al., 2008). It is argued that both sides need to be open to partnerships, and it is up to the governments to create a positive environment in which NPOs may function freely within their communities (UNAIDS, 2004b). Some authors point out that state agencies have found it difficult to work with non-profit organisations because of limited capacity, such as financial management skills, inability to meet rigid agency accountability guidelines, and costing, such as audited financial reports (Lenton et al., 2003; Mpanju- Shumbusho, 2003; Peltzer, et al., n.d.). Research indicates moreover that, in addition to the problems in partnering with government, NPOs tend to focus on competing with each other for funds and credibility within communities they serve, rather than forging a cohesive voice within the non-profit fraternity (International AIDS Alliance, 2002; Jackson, 2002). Other challenges faced by NPOs are problems of low coverage and referral of patients to other levels of care, either due to non-recognition by welfare or health care providers (Jackson, 2002; Akintola, 2004). Drew et al. (1997) estimated that most home care programmes attain only about a 1-2 per cent coverage. Wilson (2000) cites a study by Banda of seven home care projects in Zambia that found that the 1 268 clients enrolled for care represented only 4.5 per cent of the estimated 28, 000 clients in the catchment area. Woelk et al. (1997) reviewed 33 home care programmes in Zimbabwe and also found low coverage: estimated at 2-4 per cent. Moreover, NPOs

generally depend on volunteers from communities to serve as labour and receive limited support from government (Akintola, 2004; Friedman, 2002). The volunteers in turn rely strongly on extended family members of a PLWHA, especially grandparents, to provide ongoing treatment to the PLWHA and to care for grandchildren (Giese et al., 2003; Akintola, 2004; WHO, 2002b). Some authors argue that NPOs need to work and see themselves as part of a continuum of care for the PLWHA, and should link up with health clinics in the serviced community (Jackson, 2002).

Other difficulties that NPOs face relate to the quality of care provided and referral systems (Jackson, 2002). In the Woelk et al. (1997) review, the authors found that only 17 out of 33 programmes, almost half, provided even a basic minimum package of care. An ideal care package was defined as including a greater focus on caregiver training, HIV prevention, wider integration with long-term services for OVC and better direct patient care and referral (Jackson, 2002).

Nonetheless, some authors point out that services provided by NPOs are accessible to clients and their caregivers, reduce isolation and provide needed interventions, which can contribute to improved health care seeking behaviour, better quality of life and extended survival for the PLWHA (Russell & Schneider, 2000; Stephenson & Hennink, 2004). This observation is evidenced in the involvement of PLWHA and their caregivers in AIDS care, treatment, literacy and education activities, and their ability to anticipate the health and material needs of the community (Gilks et al., 1998; Blinkhoff et al., 1999; Oleja, 1999; Birdsall & Kelly, 2005; HAI; 2005). In addition, non-formal methods of education and awareness raising applied by NPOs, such as songs, storytelling, and community theatre and/or drama, offer mechanisms for health education that is culturally acceptable, effective, affordable and accessible (WHO, 1978; Shaik & Hatcher, 2004). These non-formal methods of active learning are compatible with, and promote the general principles of Primary Health Care (WHO, 1978).

Non-profit organisations that provide community home base care are especially active in prevention and care programmes that reach isolated communities and households in many sub-Saharan African countries affected by HIV and AIDS, including South Africa (Blinkhoff, 1999; Russell & Schneider, 2000; Nsutebu, 2001; Jackson, 2002; UNAIDS, 2004). The services provided are diverse, although not mutually exclusive. Services range from home

visits and nursing, information distribution and counseling, to income generation and skills development (Jackson, 2002). Research has shown that when care and support are provided, especially at a community level, people are less likely to deny their HIV status, will understand a need for prevention, increase their health seeking behaviour, and will be motivated to protect others; than when no services such as those offered by NPOs are provided, and they feel neglected by both the formal and non-formal health care system (MacNeil & Anderson, 1998; HAI, 2005c).

Thus, the literature highlights major care gaps in NPO service delivery, which include among other a lack of discharge plans from hospital to home, a lack of family and caregiver preparation, insufficient numbers of visits to the PLWHA's homes, a lack of material provision to the caregiver to provide optimal care- including foodstuff and, medication, a lack of legal advice to caregivers on issues such as disability grants and application forms, and referral to social, legal and medical services (Jackson, 2000; Ray & Mataure, 2000; WHO, 2002a, Giese et al., 2003; Akintola, 2004).

2.6.3 Non-profit organisation best practices

The notion of best practice involves the identification and use of a successful intervention or knowledge about that which has proven to work well in certain situations and contexts. In other words, best practices involve both the lessons learned, and a continuing process of learning, feedback, reflection and analysis of the situation (UNAIDS, 1999). An intervention may be viewed as a best practice if it is sustainable, and can be replicated in certain other settings, with adjustment if needed.

The literature describes a range of NPO best practices involved in supporting PLWHA and their families. In sub-Saharan Africa, best practices that are functioning well and are being replicated in different settings, such as rural and urban environments, are found in some of the sub-region's most under-served areas such as peri-urban and farming communities (Russell & Schneider, 2000; Friedman, 2002; Akinola, 2004). Examples of NPO best practices that have proven to be effective in countries in the sub-region are:

- *Grandmothers Against Poverty and AIDS (GAPA)* in South Africa. GAPA was established, based on the outcome of a longitudinal qualitative study undertaken by the Institute of Ageing in Africa (IAA) to assess the needs of grandmothers affected

by HIV and AIDS, in 2000/2001. It was later registered as an NPO. GAPA organises peer support groups for affected grandmothers, and capacitates them through education and information on HIV and AIDS, and human rights, and equips them with life skills and income generation skills. Within support groups, grandmothers share information, ideas and skills that help them to cope better with their situation. They make handicrafts and other items which they sell in their community and benefit from the income. The GAPA model is replicated in other provinces in the country.

- *Magunje* in Zimbabwe. Magunje is an income generation project for people infected with and affected by HIV and AIDS. Established by HelpAge International (Jazdowska, 1992), it capacitates caregivers through skills training in garment making, poultry faming, etc. Its members sew school uniforms, rear and sell chickens, and build irrigation systems. An aim is to encourage older people and school children to work together to promote intergenerational solidarity.
- The *Catholic Diocese Outreach Project* in Ndola, Zambia copperbelt. The project offers training to volunteers in home-based care and support to infected and affected persons, and their caregivers. Trainees are later dispatched in their communities to train and assist affected families, and empower older carers through knowledge and information on HIV and AIDS, who in turn educate their peers on the disease (Blinkhoff et al., 1999).

A key lesson to be drawn from NPO best practices that support older carers is that support for and work with older persons can benefit others. Non-profit organisations thus clearly contribute to the support of older carers in their struggle against the epidemics. They not only equip the carers with critical skills and knowledge needed to manage PLWHA, but also assist them to break away from the drudgery and routine demands of caregiving (Miller, 2000). Indeed, the literature shows that NPOs are at the forefront in mitigating the impact of the epidemics on older persons and their households (Akintola, 2004; Ferreira et al., 2001; HAI, 2003a, 2004b; 2006b). In addition, they lessen the burden of care on overstretched public health systems. However, they need material, human, infrastructural and financial resources, to enable them to improve or overcome some of their limitations such as poor coverage (Drew et al., 1997).

2.6.4 NPOs as advocates for HIV and AIDS caregivers

Advocacy aims to influence decision making with a goal to develop, establish or change policies, and to establish and sustain programmes and services (WHO, 2004). Non-profit organisations are involved in community mobilisation and the protection of PLWHA' human rights, and facilitate access to health, welfare services and education (UNAIDS, 1997; Russell & Schneider, 2000). Some NPOs such as GAPA and the Treatment Action Campaign (TAC) in South Africa lobby government ministries and submit petitions highlighting the plight and support needs of infected and affected persons, including older caregivers.

In Mozambique, some CHBC work with older carers and schools to demand subsidization of school fees for OVC. Other CHBCs lobby district education authorities and schools to help re-integrate OVC into schools (HAI, 2002a, 2003a), thus assisting older carers and improving OVC's situation and life chances. In South Africa, advocacy organisations in KwaZulu-Natal such as MUSA and Thandanani identify caregivers and households affected by HIV and AIDS and children at risk of being orphaned and vulnerable, and then create awareness, and establish links and referral relationships with relevant bodies such as social, medical, nutritional, child welfare and other support services in the community (Russell & Schneider, 2000; Sanders et al., 2005; Maher, 2006).

Research indicates that emotional and psychological support, albeit to a limited extent, is commonly provided by CHBC NPOs. Support groups empower older people by building self esteem, network, raise the visibility of older women caregivers and encourage mutual support (UNAIDS, 1999; Nokes et al., 2006). Issues of belonging, participation, access to formal sources, and identification with the local community as well as empowerment to promote change within the community may be important yet unexplored aspects of empowering and supporting older caregivers in the management of the epidemics (Boneham & Sixsmith, 2006; Knodel et al., 2006).

PART D: FORMAL CARE

2.7 FORMAL CARE

Formal care is defined here as caregiving provided by professionals to clients through an agency, either in the public sector or the private sector, for which services professionals are

compensated. Categories of formal care providers range from medical practitioners to registered nurses, therapists, social workers, dieticians and paraprofessionals such as nurse aides (Allander & Spradley, 2005). The majority of formal care professionals work in public health institutions at the primary level of the health service system.

2.7.1 Primary Health Care (PHC) approach

Primary Health Care emphasises the centrality of comprehensive, inter-sectoral action among sectors such as health, education, welfare, agriculture, housing, business and community involvement in identifying and solving community (and household) health problems (WHO, 1978; Last, 1988; McCoy & Engelbrecht, 1999; WHO, 2003).

Some literature has indicated that the multiple and complex problems presented by HIV and AIDS in communities in sub-Saharan Africa call for a PHC approach (Akinsola, 2001; WHO, 2006). Such approaches include helping individuals to recognise the severity of the HIV and AIDS epidemics in the community (Akinsola, 2001). The WHO supports a primary health model of service delivery for HIV and AIDS services that will maximise the role of PHC, and promote a developmental agenda with an emphasis on community empowerment and participation (Rifkin & Walt, 1986; WHO, 2006). However, comprehensive PHC has not been achieved in many developing countries, although based on principles of effectiveness, equity, social justice, community involvement, mainly due to a lack of interest on the part of funders in investing in acute health interventions that are likely to achieve only short-term and immediate health improvements (Zwarenstein & Baron, 1992; Baum & Sanders, 1995; WHO, 1996).

Research carried out in Botswana indicates that when PHC personnel support family members affected by HIV and AIDS with appropriate information, such as how to access available resources in their communities and establish effective social networks, hope in the future is restored for both the PLWHA and the family (Akinsola, 2001; Horizons, 2004c; UN, 2004b). Work done in other affected developing countries such as south India, indicates that comprehensive support by government and NPOs to PLWHA and their caregivers alleviates the burden on caregivers. In south India, districts provide medical services, counselling, nutrition, dental care, social support and referral services to relevant government institutions and traditional medicine services (Horizons, 2004c).

In South Africa the PHC system began in earnest in 1994, with an explicit goal of developing a unified national Health System that is organised at national, provincial and district levels. The PHC system provides free health services to pregnant mothers, children under five years of age and older persons. Health clinics have been built in urban centres and rural areas to increase access to primary-level health care (Pillay et al., 1998; Department of Health, 2000; Joubert & Bradshaw, 2000; Benatar, 2004). The primary care services provided free to eligible clients at over 3 500 PHC clinics include prevention, and the care and treatment of diseases of older persons (DoH, 2000; Joubert & Bradshaw, 2000). However, in the transformation of South Africa's health services to PHC, dedicated older person services were largely marginalised or even withdrawn. The few remaining services are concentrated in urban areas and thus inaccessible to older persons in rural areas (Joubert & Bradshaw, 2000; Benatar, 2004), where the majority of older caregivers reside.

Research indicates that such marginalisation includes the preventive, curative and rehabilitative needs of older clients, which for the main part have been integrated into general sessions at community clinics at primary care level (Benatar, 2004). Moreover, numerous community nurses were redeployed from geriatric services to assist in child immunisation programmes (Benatar, 2004). Client dissatisfaction with services at public health institutes is documented in a number of studies (Myburg et al., 2005; Westaway, 2003; Wouter et al., 2001; Househam, 2009). The grievances include long waiting times, client overload, poor staff attitudes and morale, referral problems and shortages of medicines.

Certainly, the PHC system and its associated challenges do not currently meet the health needs of older caregivers to PLWHA and OVC. They are neither enabled to sustain or improve their own health. Older caregivers suffer a number of physical and mental health problems, relating to caregiving, over and above ailments common in old age, and diminishing energy and stamina. Among these conditions are swollen limbs, hypertension, headaches, dizziness, chest pains and stomach disorders (Valenti, 1995; WHO, 2002a; Dayton & Ainsworth, 2002). Emotional problems include anxiety, insomnia, stress, burn out, and feeling over-burdened (WHO, 2002a; Maher, 2006; Knodel, 2006).

Intervention efforts such as training and integrating older caregivers in PHC service delivery have been undertaken in some developing countries – in Mozambique, Botswana and India, for example (HAI, 2003a; Akintola, 2004; Horizons, 2004c). An evaluation of such

interventions indicates that older persons become an important and effective resource in the prevention and mitigation of the spread of HIV and AIDS (HAI, 2003a; WHO, 2002a). Thus, an opportunity exists in South Africa for PHC, with its principle of community involvement, to do more for older caregivers. Indeed, avenues along which caregivers' capacity and willingness to help their sick children may be utilized need to be explored. They may then be trained and involved in counseling programmes and monitoring treatment adherence at home as has been demonstrated in other highly affected countries such as Botswana and Mozambique. Policy on PHC, and inclusion (or exclusion) of older clients in policies are reviewed fully in Chapter 3.

2.8 OLDER CAREGIVERS' KNOWLEDGE ON HIV AND AIDS

As noted above, the literature provides evidence of the major challenge that HIV and AIDS poses for older caregivers, families and communities, as well as Primary Health Care in the SSA region and South Africa. Among SSA countries, South Africa carries the second heaviest burden of HIV and AIDS after Swaziland (UNAIDS, 2004a/06). Despite extensive international research, no cure for the disease has been found. Progress in the area of HIV infection prevention was shown in scientific papers presented at the Toronto XVI 2006 HIV and AIDS international conference. Of interest is that scientific papers on caregiving presented in the conference indicated that older carers, especially older women in Africa, experience great hardship and lack resources to help them in their caregiving, and thus support them and the contribution they make.

The prevalence of HIV continues to escalate in some world regions, especially in poverty stricken developing regions of sub-Saharan Africa (UNAIDS, 2006). At a micro level, individuals and families have difficulty in coping with the stresses of related caregiving. At a meso level, the resources of NPOs are over stretched as they try to meet needs and demands of communities affected by the epidemics. At a macro level, formal care systems, specifically the PHC system in South Africa, experiences similar difficulty in trying to manage the epidemics, as shown in Human Sciences Research Council (HSRC), national surveys (Shisana & Simbayi, 2002, Shisana et al., 2005) and Department of Health ante-natal syphlis surveys (2004,2005). Seemingly, non-profit organisations, through their CHBC programmes, have come to the rescue of the overstretched PHC system, but have their own limitations,

such as a dependency on volunteers, low coverage, a limited technical skills base and financial constraints.

Affected older persons who ultimately carry the burden of care for PLWHA and their grandchildren at a household level thus form a crucial part of the informal safety net on which PLWHA and OVC ultimately rely. Older women render a valuable contribution to the care management of HIV and AIDS (PANOS, 1990; Ferreira et al., 2001; HAI, 2005c) and within the family and affected households, and in this way are a crucial link in the continuum of care to PLWHA and OVC. Thus, it is widely argued in the literature that older carers should be supported, to enable them to cope with the double burden of caregiving and old age (Joubert & Bradshaw, 2000; HAI, 2003a; Knodel & Im-em, 2004; Orner, 2006).

As several authors have indicated, decisions on the nature of such support should be informed by an understanding of the complex situation of older caregivers. The support should be targeted moreover to resources within and outside relevant households. Goals such as strengthening the family, removing barriers to social assistance, inclusive and effective health services, improved economic environments, and social networks for parenting grandparents are factors that have been highlighted (Dolbin-MacNab & Targ, 2003; Hayslip & Kaminski, 2005).

Policies on AIDS and older persons' integration in such policies and responses are reviewed in Chapter 3. The review of the relevant literature in Chapter 2 has pointed to a need to respond to the situation and support needs of older carers, against the provisions of international, continental, sub-regional and national bodies, and an identification of gaps in policy action.

CHAPTER THREE: REVIEW OF RELEVANT INTERNATIONAL, REGIONAL AND NATIONAL INSTRUMENTS, POLICIES AND PROGRAMMES

3.1 INTRODUCTION

A review is undertaken in this chapter of international and Africa regional instruments, policy frameworks, and national policies and programmes aimed at the advancement of older individuals' human rights, development and support in general, and responses to persons affected by HIV and AIDS in particular. The review includes national sectoral policies, strategic plans and programmes, and legislation, as part of African governments' response in their commitment to employing and implementing the international and regional instruments. In addition, community responses to the support needs of older persons in the era of HIV and AIDS are examined.

The review is aimed overall at an identification of strengths and weaknesses of existing, frameworks, policies and programmes: in particular, gaps in responses to the support needs of older persons rendered vulnerable by the epidemic. The review will serve as a basis for the development later in this dissertation of an appropriate policy framework to guide policy reformulation or development to support such persons. Policies on HIV and AIDS, ageing and older persons, human development and Primary Health Care are reviewed. Gaps in these policies, particularly the exclusion of affected older persons, are identified as are opportunities to fill the gaps, specifically through Primary Health Care strategies and interventions, identified.

3.2 INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

Instruments to protect the human rights of individuals have been developed by international bodies such as the United Nations (UN). Such instruments include the UN Declaration of Human Rights (1948), the UN Principles for Older Persons (1991), and the Vienna Declaration (1993) - adopted in the World Conference on Human Rights. Human development instruments, such as the UN Millennium Declaration (2000), similarly provide a basis for the protection of the rights of all, including persons afflicted with or affected by contagious diseases such as HIV, tuberculosis (TB) and other conditions. The Universal

Declaration of Human Rights (1948) embodies 30 articles that deal specifically with human rights. Article 25 emphasises the right of every individual to enjoy an adequate standard of living to ensure his/her health and well-being, or that of his/her family, and mentions older persons specifically as constituting a vulnerable group whose rights should be protected by governments. The declaration does not provide a mechanism to enforce the provisions, and Member States are left to honour their commitment to the declaration, and to be guided by the provisions in the development of policy and the implementation of programmes. In practice, however, older persons' participation in social and political processes, and their ability to exercise their human rights, vary across countries.

The Vienna Declaration on human rights (UN, 1993) emphasises the promotion and protection of individuals' human rights as a global priority. Its Programme of Action provides Member States with a framework to carry out a comprehensive analysis of their human rights system and the machinery for the protection of citizens' human rights - in order to enhance and thus promote a fuller observance of those rights in a just and balanced manner. Sections (i)(21)(22)(23) and (24) of the declaration mention the need to protect the rights of certain vulnerable groups in society such as children, disabled persons and migrants, but make no explicit reference to older persons. However, implicit in subsection (i)(24), on the promotion and protection of the rights of vulnerable groups – especially in the areas of education, health and social support, is consideration of the rights of older persons.

3.2.1 International human development instruments

Instruments that deal specifically with human development focus on poverty reduction and economic growth broadly, and are inclusive of HIV and AIDS and health care strategies intended to benefit infected and affected persons. Among these instruments are the UN Millennium Declaration (UN, 2000) and the subsequent Millennium Development Goals (MDGs) (UN, 2002); and the UN Declaration of Commitment on HIV and AIDS (2001).

The UN Millennium Declaration states that "Only through broad and sustained efforts to create a shared future, based upon our common humanity in all its diversity, can globalization be made fully inclusive and equitable" (UN, 2000). Following on the UN Millennium Declaration, was the adoption of a set of eight development goals, known as the UN Millennium Development Goals (MDGs), which constitute an action plan for the

implementation of the Declaration (UN, 2000). The MDGs have built-in targets to be achieved by signatory Member States by 2015. Broadly, the MDGs promote poverty reduction and the realisation of human rights as overarching goals for development co-operation. Although they not refer to older persons specifically, some of the goals, once achieved, may serve to improve the situation of older carers to PLWHA and OVC in sub-Saharan countries. Other goals potentially relevant to older persons are those aimed at halving the proportion of people living in poverty (MDG1) – among which are numerous older persons; redressing gender inequality and forging women's empowerment (MDG3) (see also UNFPA, 2002a; HAI, 2003a, 2004); and halting and starting to reverse the spread of HIV and AIDS (by 2015) (MDG6) (UN, 2000).

However, the MDGs focus on development of the youth. Indicators to redress gender inequality and achieve other goals are set narrowly, and in effect have an upper age limit. By focusing on education and literacy for girls and young women, for example, the goal overlooks the fact that women of all ages in sub-Saharan countries and other developing regions fall behind men in literacy and education (HAI, 2005b). A baseline study on HIV and AIDS in Bangladesh showed that older men had on average four more years of education than older women, and average incomes more than five times higher than those of women in their age group (Chaklader, 2004). Likewise, a study of gender in education in Africa (Kitetu, n.d.) established that although some African governments such as Kenya and Ghana have affirmed female education as a priority by increasing female school enrolment, females are still disadvantaged in practice by cultural gender norms (UNAIDS, 2004b). Thus, older persons are neither mentioned in the MDGs, nor are they included in development agendas (Aboderin & Ferreira, 2008).

Nonetheless, the UN Declaration of Commitment on HIV and AIDS, adopted in 2000 (UN, 2000), is aimed at addressing the problem of HIV and AIDS in all respects, and securing a global commitment to enhance co-ordination and intensification of international, regional, and national efforts to combat HIV and AIDS in a comprehensive manner. The declaration has gone some way in correcting the anomalous exclusion of older persons in the MDGs. It refers specifically, for example, to the family more than once, and in particular to older persons, in the context of the "social and economic impact of the epidemics at all levels of society". Article 68 refers specifically to women and the elderly in their role as caregivers in families affected by HIV and AIDS. It also addresses their special needs, such as a need for

social protection, essential economic services and other relevant support measures specifically relating to caregiving. The declaration calls for various role players, globally, regionally and nationally, as well as governments, business, non-profit organisations, communities and donor agencies to work together to combat HIV and AIDS, and to ensure the universal principles of participation, non-discrimination, and the human rights of those infected with and affected by HIV and AIDS. Thus, the declaration provides explicitly for older persons' integration into these processes.

3.2.2 Internationally agreed policies and plans relating to older persons' needs

Instruments that focus specifically on older persons include the UN Principles for Older Persons, adopted in 1991 (UN, 1991). The document embodies five main principles for the realisation of older persons' rights: i) Independence, which includes access to adequate food, water, shelter, clothing and health care; ii) Participation, which intends that older persons should participate actively in the formulation and implementation of policies that affect their wellbeing and should share their knowledge and skills with younger generations, as well as be able to form organisations and associations; iii) Care, which proclaims that older persons should benefit from family care, health care and be able to enjoy human rights and fundamental freedoms when resident in a shelter, care or treatment facility; iv) Self-fulfilment, which states that older persons should pursue opportunities to develop their potential fully, through access to educational, cultural, spiritual and recreational resources within their society; and v) Dignity, which states that older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse, and should be treated fairly and be valued independently of their economic contribution (UN, 1999). The UN International Year of Older Persons, celebrated in 1999, supported the Principles for Older Persons as proclamations in recognition of humanity's demographic "coming of age" (UN, 1999).

More recently, the UN Madrid International Plan of Action on Ageing 2002 (MIPAA) was adopted by 159 Member States within the Second World Assembly on Ageing, held in Madrid, Spain in 2002. The MIPAA has three priority directions (see UN, 2002b): a) Older persons and development; b) Advancing health and well-being into old age; and c) Creating an enabling and supportive environment. According to the first priority area, the expectations of older persons and the economic needs of society demand that older persons be enabled to

participate in the economic, political, social and cultural life of their community. Hence, poverty reduction strategies must increase their focus on the poorest and most vulnerable older persons, especially older women, and enable them to achieve their basic human rights and to live in dignity (UNFPA, 2002a). In this respect, the empowerment of older persons and the promotion of their full participation in society are essential elements in the fight against older persons' poverty, especially where they are affected by HIV and AIDS.

The second priority area, which promotes the advancement of health and well-being into old age, declares that older persons should be enabled to access preventive and curative care, including rehabilitative care and sexual health care. The priority emphasises the importance of health care services for the older population, including the training of personnel and facilities to meet the special needs of the older population. The third priority direction calls for the creation of enabling and supportive environments for older persons in order to enhance their capabilities, which includes access to basic services such as clean water and adequate food (UN, 2002b). An overall thrust of MIPAA is that older persons should be fully included in development efforts and programmes aimed at reducing poverty and forging development – as both contributors to and beneficiaries of such efforts.

The MIPAA has a section on HIV and AIDS that commits Member States to recognise the contribution that older persons make to development in their role as caregivers to sick adult children and as surrogate parents to young children orphaned as a result of the disease. The instrument encourages governments to improve their assessment of the impact of the disease on older persons and to "introduce policies to provide in-kind support, health care and loans to older caregivers to assist them in meeting the needs of [adult] children and grandchildren in accordance with the Millennium Declaration Goals" (UN, 2000). Furthermore, it calls for adequate information, training in caregiving skills, medical treatment and care, and social support to older caregivers. It argues specifically for the enhancement and recognition of older persons' contribution to development and their roles as caregivers in the era of HIV and AIDS.

A strength of the MIPAA in this regard lies in its focus on contributions made by older persons affected by HIV and AIDS and their related support needs. The plan of action makes important policy connections moreover between older caregivers' needs and the needs of the

children for whom they care. Significantly, the plan commits signatory governments to extend to older persons the "right to development."

3.2.3 International HIV and AIDS instruments in response to the epidemics and older persons' needs

The UN Declaration of Commitment on HIV and AIDS was adopted by the General Assembly in its 26th special session held in June 2001, convened in accordance with resolution 55/13, as a matter of urgency, to review and address the challenge of HIV and AIDS. The declaration notes that "the full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV and AIDS pandemics". It also sets concrete, time-bound targets for the introduction of national legislation and other measures to ensure the respect of rights in regard to education, inheritance, employment, health care, social and health services, prevention, support, treatment, information and legal protection. A strength of the instrument lies in its encouragement of national governments to develop legislation to protect the rights of infected and affected persons. Older persons are implicitly recognised in the instrument, as it mentions the realisation of human rights and universal freedoms for all. However, Member States are not legally bound to implement commitments in the declaration.

The Valletta Declaration (UN/HtA, 2005), on the other hand, developed in an expert meeting within the Commonwealth People's Forum held in Malta in 2005, aimed to draw attention to the effects of HIV and AIDS on older persons among heads of state and to influence the development of policy to mitigate these effects throughout the Commonwealth (of which South Africa is a member). A particular strength of the declaration lies in its being the first global instrument to focus specifically on older persons and HIV and AIDS, and to call for dedicated policy to support affected and infected older individuals. Other strengths lie in its ten recommendations, which call *inter alia* for the integration of older persons' support needs in general with their social and household needs. The recommendations are addressed to governments and civil society, six of which deal specifically with the support needs of older caregivers.

The first recommendation calls on governments to recognise older caregivers by providing them with political, social and economic support' without this recognition, they will

otherwise be excluded in HIV and AIDS policy and programme development and implementation. Recommendations 2 and 6 call on both governments and civil society to incorporate affected and infected older persons' needs in their responses to HIV and AIDS, as their needs are similar to those of the broad society. The recommendations call for responses that promote intergenerational cohesion. Thus, older persons' needs should not be addressed in isolation or as a vertical programme, but integrated within other interventions. Recommendation 7 emphasises the importance of appropriate prevention and education strategies targeted to, and/or potentially mediated by, older persons. Recommendation 8 calls on governments and international bodies to support research on the impact of HIV and AIDS on older persons, including the collection and disaggregation of data on infection rates by age and gender. Recommendation 9 urges formal and informal institutions, in tandem with the media, to play an active role in the eradication of stigma surrounding persons and households affected by HIV and AIDS. Lastly, Recommendation 10 calls on governments to introduce and implement policies that make anti-retroviral therapies available to all who need them, including older persons and those in their care. A particular strength of the Valletta Declaration lies in its recognition of a need to address HIV and AIDS related problems through an intergenerational solidarity approach. Thus, the exclusion of any section of society, especially older persons, in responses to the epidemics is to be discouraged.

3.2.4 Primary Health Care, HIV and AIDS, and older persons' needs

The Primary Health Care (PHC) strategy, defined as “essential health care based on practical, scientifically sound and socially acceptable, appropriate strategies and technologies, easily accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of development …”, was adopted in Alma Ata in 1978 (see WHO, 2003). Consequently, Member States should commit themselves to providing and ensuring “health for all” by the year 2000. However, in sub-Saharan African countries the PHC policy provisions have been more symbolic than real (UNDP, 1991).

Nonetheless, the adoption of the PHC strategy by the World Health Organization was a milestone in the formulation of health care delivery policy globally. It was envisaged that the first level of contact for individuals, the family and community with the national health system should be at the local level. Thereafter, patients could be referred, if needed, for

investigation and treatment at secondary and/or tertiary health care levels. Primary Health Care comprises eight elements: i) Education concerning prevailing health problems and methods of preventing and controlling them; ii) promotion of food supply and proper nutrition; iii) adequate supply of safe water and basic sanitation; iv) maternal and child health care, including family planning; v) immunization against major infectious diseases; vi) prevention and control of locally endemic diseases; vii) appropriate treatment of common diseases and injuries; and viii) provision of essential drugs (WHO, 1978). Coupled with the elements are principles underlying PHC, which are in accordance with principles promoted in the international human rights instrument (1948) such as social justice, equity, human dignity, and giving priority to the most vulnerable groups in society. However, the extent to which PHC policies in SSA countries encompass equity, community participation, inter-sectoral collaboration and affordability is questionable. Nonetheless, a major strength of the PHC approach lies in its recognition and prioritisation of the health care needs of vulnerable groups, such as the poor, among which is a large number of older persons (UN, 2001b).

Significantly, the WHO has developed a document that promotes age-friendly PHC, namely 'Towards Age-friendly Primary Health Care' (WHO, 2004a). The "age-friendly" principles built upon in the document address four major areas: i) Information, education, communication and training, including staff training in clinical geriatrics and approaches to patient education; ii) health care management systems, i.e. adaptation of procedures, such as registration, to the special needs of older persons; iii) adoption by PHC of systems that support a continuum of care both at the community level and at secondary and tertiary care levels, including the keeping of records of the client and the provision of social services to the clients; and iv) the physical environment, i.e. accessible and easily readable signage, and clean and comfortable centres (WHO, 2004a).

Despite their strengths, the implementation of the PHC principles 30 years after their adoption has been variable in many developing countries, especially in sub-Saharan Africa. Inadequacies in the translation of policies into implementable programmes are contended to have contributed to, if not produced, poor national health outcomes across the sub-region (Dugbatey, 1999). This impasse is largely due to a lack of resources; internal and cross border migration trends that stretch limited public health resources; and the emergence of communicable diseases such as HIV (WHO, 2003).

The governments of several SSA countries have been slow moreover to implement provisions of international instruments, through a lack of awareness or commitment, a lack of political will, and/or a selective, as opposed to a comprehensive, approach in programme implementation owing to a lack of resources (both financial and human) (De Maeseneer et al., n.d.).

3.3 AFRICA REGIONAL INSTRUMENTS

At a regional level, Africa's responses to human rights, human development, health and the HIV and AIDS epidemics are informed by regional inter-governmental agencies such as the African Union, sub-regional bodies such as Southern African Development Countries (SADC), and strategies such as those of the New Partnership for Africa's Development (NEPAD). In conjunction with the availability of the instruments for policy and practice in general, are specific instruments for honouring the rights and responding to the needs of older persons.

Regional bodies that have developed policies and responses represent governments, coalitions of civil societies, community based organisations, youth, the media and the private sector as stakeholders. However, while various regional role players have been involved in the drafting of the instruments, older persons and organisations that represent them have tended to be overlooked and excluded (African Union, 2003; Du Guerny, 2001). Such oversight may be due to “ageist” attitudes, whereby older persons are viewed as a spent force and approaching the end of their life (Nhongo, 2003). Thus, older persons tend to be viewed largely as welfare beneficiaries and dependents, rather than as contributors to family, community, social and economic life, but who, as in the present case, may be actively involved in addressing and managing social problems such as HIV and AIDS and other developmental challenges (HAI, 2002a).

3.3.1 Regional human rights instruments and older persons' rights

The African Union (AU), previously the Organisation of African Union (OAU), is the main regional body charged with the development of Africa-wide binding instruments. Among these instruments is the African Charter on Human and Peoples' Rights (the Banjul Charter), adopted in Nairobi, Kenya in 1981 (OAU, 1981). The charter was drafted as a result of a

concern of regional heads of state about a lack of respect shown to the rights of Africa's citizens by their leaders. However, the generality of the charter's provisions is similar to that of rhetoric of the African Union, regarding, for example, women's rights (Rebouche, 2006), which many sub-Saharan African countries fail to respect fully. As a consequence, 27 years since its adoption, several African countries still lack a political will to respect and protect the human rights of citizens - as witnessed, for example, in the mass killings as a result of ethnic conflict in Rwanda in 1994 (Mamdhani, 2003) and continuing extreme violation of the human rights of Darfurians in Sudan. Human rights violations in Darfur have resulted in more than 700, 000 displaced persons, 10 per cent of whom are older persons (HAI, 2005a)

Nevertheless, a particular strength of the OAU charter lies in Article 2, which argues for recognition that all should enjoy the rights and freedoms in the charter without distinction of any kind, such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. More pertinently, Article 9 of the charter states that "Every individual shall have the right to receive information," relevant to his/her wellbeing and development. Article 18(4) further notes that "the aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs." A progressive document among the regional instruments is the document pertaining to the New Partnership for Africa's Development (NEPAD), discussed below.

3.3.2 Regional instruments on human development and older persons' development

In efforts to forge unity and good governance and to promote economic and social development in Africa under a single regional structure, the OAU earlier developed various instruments to give concrete form to such efforts. Among the instruments are The Lagos Plan of Action (LPA) and Final Act of Lagos (1980-2000), and the New Partnership for Africa's Development (NEPAD) (2001). The former two documents were adopted by the heads of state of countries belonging to the OAU in Nigeria, Lagos, in an extraordinary session devoted to economic problems on the continent. The LPA incorporates programmes and strategies to promote self-reliance, development and cooperation among African countries. However, the LPA makes no mention of the development of programme(s) to ease the socio-economic difficulties faced by older persons in the region, the majority of whom live on less than a dollar a day (HAI, 2005a). The plan makes no mention moreover of issues such as

human rights and support for the poor, in which group the majority of older persons fall (HAI, 2003b). The New Partnership for Africa's Development (NEPAD) was formulated as a mechanism to strengthen the aim of the LPA and other regional instruments (NEPAD, 2001). NEPAD was adopted as a programme of the African Union at the Lusaka Summit, Zambia in 2001. The document is designed to help Africa and her people to overcome regressive political regimes and to enable her to achieve peace, economic growth and development. It states that "The New Partnership for Africa's Development is a pledge by African leaders, based on common vision and a firm and shared conviction, that they have a pressing duty to eradicate poverty and to place their countries, both individually and collectively, on a path of sustainable growth and development, and at the same time, to participate actively in the world economy and body politic" (NEPAD, 2001:1). Importantly, NEPAD recognises the importance of democracy, human rights, and the rule of law for economic development explicitly. A significant improvement of NEPAD as an instrument to support development, compared to other Africa regional instruments, is that it has developed its own code of governance and system for "peer review". The document looks outward, moreover, as well as inward for solutions to development barriers in Africa. However, its pledges on human rights are vague, and it is silent on older persons' development needs.

3.3.3 Regional instruments and older persons' needs

A number of regional instruments address older persons' needs specifically. The African Union's Policy Framework and Plan of Action on Ageing, drafted parallel with the UN Madrid International Plan of Action on Ageing (MIPAA), was adopted in the 38th Ordinary Session of the Heads of State and Government in Durban, South Africa, in July 2003 (AU, 2003). The main objective of the plan is to guide AU Member States as they design, implement, monitor and evaluate appropriate integrated national policies and programmes to meet the individual and collective support needs of older persons (HAI, n.d.). The policy framework identifies barriers to older persons' well-being in the region, and provides recommendations to remove those barriers. Among issues highlighted in the policy framework are human rights. Significantly, the framework recommends that Member States abolish all forms of age-based discrimination. Regarding health, the framework, it urges Member States to undertake to ensure that older people's rights to appropriate health care are legally constituted and guaranteed. It also identifies gender as an important issue and encourages Members States to incorporate ageing into policies relating to gender. Moreover,

the framework identifies HIV and AIDS specifically as being a major problem facing older persons in Africa, and urges Member States to undertake to support affected older persons in their contribution to the fight against the disease. Finally, the framework encourages the integration of older persons' interests in state policies and interventions in general.

3.3.4 Regional HIV and AIDS instruments and older persons

HIV and AIDS related morbidity and mortality in the continent currently undermine the development efforts of African regional bodies severely. Encouragingly, the African Consensus and Plan of Action to Overcome HIV and AIDS (AFD, 2000) acknowledges the efforts of numerous role players in the fight against the epidemic. The plan emanated from a meeting between African leaders convened by the African Union and held in Addis Ababa, Ethiopia in 2000, which deliberated on ways and means to overcome the HIV and AIDS epidemic and its effects in Africa. Among the strategies proposed is the development of strong leadership at all levels of society, starting from the family and community, to national and regional levels. Clause 2.11 of the plan mentions older persons specifically as being stakeholders in the community, whose important role and responsibility must be supported and developed to enable them to become full allies in the fight against the epidemics. A particular strength of the plan lies in its call for older persons' full integration in efforts to fight the epidemics.

The Abuja Declaration (2001) emanated from a special summit of African heads of states and government of the African Union (AU), held in Abuja, Nigeria in 2001, to discuss problems presented by HIV and AIDS, tuberculosis, malaria and other infectious diseases in Africa. The declaration identifies groups at high risk of HIV infection, among whom are youth and women (i.e. young females). The declaration commits signatory governments to develop a multi-sectoral strategy to combat the epidemics, which should include sectors such as trade unions, the media, religious organisations and youth. However, the declaration is exclusive in its approach in that it overlooks older persons and their role in the care management of the epidemic in African communities and households. While youth groups and PLWHA organisations are viewed as allies in combating the spread of the epidemic, no mention is made of older persons' organisations. Nevertheless, the AU Policy Framework and Plan of Action on Ageing (2003) identifies older persons as having a role in the fight against the

epidemic and indicates 13 important areas of concern in which they need support, such as health, food and nutrition, housing and living conditions, among others.

The AU policy framework refers specifically to an urgent need to protect, support and educate older persons regarding HIV and AIDS, and to allocate more resources such as specific budget to support growing numbers of older persons caring for the sick and OVC, and families and support systems in communities. The framework includes a section on the family, and makes recommendations for the development of policies that reposition and strengthen the family to enable it to respond to the problems that affect families. Actions on HIV and AIDS recommended in the plan include: i) Ensuring that policies and programmes recognise older people as major care providers to sick family members and vulnerable and orphaned grandchildren; ii) providing support to those caring for and affected by AIDS and other epidemics; and iii) strengthening community based care mechanisms to ensure that older people who are care givers receive support. The instrument benefited markedly from the involvement of older persons' bodies such as HelpAge International's Africa Regional Development Centre in its formulation, as the centre actively canvassed older persons' opinions and gathered information on their difficulties and needs, and incorporated same in the policy framework.

A document that focuses on older persons in the era of HIV and AIDS in southern African countries is the UN Policy Framework on HIV/AIDS and Family Well-being (UN, 2004b), developed in a workshop with participants from several southern African countries, held in Windhoek, Namibia in 2004. The workshop followed on special sessions of the UN General Assembly sessions on HIV and AIDS (UN, 2001) and Social Development, aimed at developing a strategic policy framework to assist governments to strengthen the capacity of families and family networks to cope. The Namibian workshop aimed moreover to promote the achievement of Millennium Declaration Goal # 6, which deals with the combating of HIV and AIDS, malaria and other communicable diseases (Target 7: by 2015). The workshop participants explored the impact of the epidemics on families and how they cope in the sub-region specifically.

A strength of the Namibian workshop document (UN, 2004b) lies in its multigenerational approach to addressing the effects of the epidemics, that is inclusive of older persons. The workshop report, which presents a policy framework, argues that while general HIV and

AIDS policies in the sub-region address the effects of the epidemics on individuals in different age groups separately, they tend to overlook the effects on families and communities as a whole, including the specific support and other needs of older members. The report highlights the valuable contributions that older persons make to the care management of the epidemic, and that such contributions are largely unrecognised and unsupported. It proposes a shift of focus, whereby policies and programmes respond to the needs of whole families in a comprehensive way, inclusive of older members (see Ferreira, 2006), who it views older members as crucial role players in affected households. The report proposes seven desired outcomes of future policies, namely: i) Reduced risk for and prevented spread of HIV and AIDS; ii) avoided stigma and discrimination; iii) supportive family and community networks; iv) diminished economic vulnerability; v) improved care and service provision; vi) mitigated effects of a generation of orphans; and vii) intergenerational cohesion.

An important document aimed at forging development in Africa, although not developed by African leaders, is the Commission for Africa Report (CfA) (2005), which emanated from the Commission for Africa set up in 2004 by the British Prime Minister at the time. The Commission comprised 17 influential African and non African experts in the areas of politics, business, economics and other important social areas. Among pressing issues addressed were poverty, and the HIV and AIDS epidemics in the continent. Regarding the fight against AIDS, the report recommends that "special emphasis should be placed on the participation of excluded groups… such as AIDS widows, children, older persons in the design of HIV and AIDS instruments such as health policies, strategies, programmes and messages" (CfA, 2005: 199). The report argues moreover for special cash transfers to be made to older caregivers of vulnerable children, since such measures have been proven to increase school attendance by 90 per cent and to improve child nutrition in places such as Zambia and Namibia (CfA, 2005: 203). It further commits the African Union to support African countries to develop national strategies inclusive of marginalised groups. Thus, the report agrees with the notion of supporting and addressing older persons' vulnerability, not least in their role of raising "children orphaned by AIDS."

Given the availability of the above instruments and documents, and Member States' commitment to them, the task must now be for the governments of countries affected by HIV and AIDS to review their existing policies, strategic plans and programmes against such instruments; to incorporate recommendations of recent, international and regional instruments

and frameworks in policies and plans, and particularly to develop responses that will benefit older persons and their households. These actions should include an integration of social services, targeted approaches, and financial support and policies that are inclusive rather than exclusive of older caregivers.

3.3.5 Primary Health Care (PHC) and older persons' health needs

The Africa region has no specific Primary Health Care policy document. African countries have followed different strategies to adopt and implement the World Health Organization's (WHO) Primary Health Care principles. However, because of the slow pace of implementation of PHC principles in African countries, health ministries adopted the Bamako Initiative (BI) document in Mali in 1987 as a strategy to accelerate PHC implementation (WHO/UNICEF/Government of Mali, 1999). The initiative's central thrust is to revitalise PHC at district level. It focuses on three complementary issues: i) A need for PHC self-financing mechanisms at district level, especially a revolving fund for essential drugs; ii) encouragement of social initiatives to promote community participation in policies on essential drugs and child health; and iii) ensuring a regular supply of essential drugs of good quality at lowest cost in support of PHC. In 1988, the WHO formulated "Guidelines for Formulating National Drug Policies." The guidelines were first adapted for the Africa Region in 1993 and the current version (WHO/AFRO/ED/01.5) was published in 2003. The document has particular relevance in that it promotes community involvement through health committees or boards, and attempts to create an environment conducive to community participation in general. However, implementation of PHC principles at the district level relies heavily on lay persons, such as community or village health workers and traditional birth attendants – most of whom are older women, especially in under served areas such as rural areas. The BI does not offer policy proposals on how lay persons who implement PHC principles may be integrated formally in the formal health system, in respect of recruitment, training, support and supervision. Neither does it indicate how the health care needs of vulnerable groups such as older persons may be promoted and protected.

3.4 NATIONAL RESPONSES: POLICIES, STRATEGIC PLANS, PROGRAMMES AND LEGISLATION

Relevant national policies, strategic plans and programmes in response to human rights, human development, HIV and AIDS, older persons and PHC in some sub-Saharan African

countries are reviewed in this section. A specific review is then undertaken of the situation in South Africa, from an historical perspective, to assess the government's response to older persons' needs in general and to HIV and AIDS in particular. Specific ministerial responses to the epidemics such as policies, strategic plans, programmes and legislation are reviewed. Sectoral responses examined specifically are those of the Presidency, and the ministries of Social Development, Health, Education, Housing and Transport. Employment of an historical perspective is essential to a review and understanding in this case, to be able to evaluate what has been achieved and what is lacking. First, definitions are given of the concepts of policy, strategic plan, programme and legislation, as they will be used below.

A policy is a social contract in a specific area of fiscal allocation and service provision, entered into by a government with its citizens, which citizenry elected the government into place. A policy is more than an intention, or a statement of intent; it represents what the government has undertaken to act upon and to deliver to the people (Walt, 1994).

A strategic plan is an organisation's or a government's process of defining its strategy or direction, and making decisions on the allocation of resources to pursue this strategy, including economic and human capital.

A programme is a system of projects and/or services intended to meet a public need.

Legislation is a set of acts of parliament and laws intended to protect its citizens' human and legal rights against abuse or violation by authorities, other bodies and groups, and individuals (Walt, 1994).

3.4.1 Country-specific human rights codes and older persons' rights

Most countries in sub-Saharan Africa have formulated policies, plans and programmes to respond to the challenges of human rights abuse, human development, older persons' needs, Primary Health Care delivery, and the effects of the HIV and AIDS epidemics. However, as pointed out, the implementation of the policies and plans has been variable.

Under colonial rule most African people suffered abuse of their human rights. Indeed, even under post-colonial rule, new black political elites perpetuate human rights abuse against

citizens, depicted as a “culture of impunity” by international human rights bodies (Manby, 2004). Although some countries have a constitution with a bill of rights, the human rights of their citizens are still at risk of violation. In Swaziland, respect for human rights has been shown to be under threat, as shown in media reports of civil society pressing for democratic change (African Development Bank, 2005-2009).

Nonetheless, some SSA governments have attempted to redress these situations by developing policy documents to protect citizens' human rights. The Botswana government developed a constitution that bars unfair discrimination (Botswana Human Development Report, 2000). However, the document makes no mention of older persons' rights.

Some SSA countries undermine their citizens' right to participate in policy and law making processes openly. In Lesotho, the formulation of government policy and legislation takes place behind closed doors and no consultation is provided for (Lesotho Council of NGOs, 2006). By implication, vulnerable groups such as older persons and their representative organisations are excluded in processes to formulate policies and legislation that affect them.

The exclusion of certain sections of society, such as lay older persons, from the development of important national documents, such as a country's constitution, appears to be the order of day in numerous African countries. Kenya developed a draft constitution, and although a product of wide consultation, no mention is made of the involvement of older persons or their representative organisations in the drafting process (Human Rights Watch Kenya, 2005). Discrimination against PLWHA and their carers infringes on their human rights, and contributes not only to the stigmatisation of these persons but their being subjected to various forms of abuse as well. Research in four Nigerian states found evidence of discriminatory and unethical AIDS related behaviour among health professionals. Abuses included denial of care and breaches of confidentiality (UNAIDS, 2004b). Although many SSA countries have achieved a great deal in developing constitutions and policies to protect citizens’ human rights, more needs to be done to hold governments to account when they fail to uphold provisions in national instruments and commit practices that are not rights based.

3.4.2 National human development and older persons’ development needs

Sub-Saharan African countries are plagued by endemic poverty and lag behind on most development indices (Aboderin & Ferreira, 2008). Indicators show widespread poverty and

large inequalities in access to basic services. The Human Development Index (HDI) places a middle income country, Botswana, at 131 (Cleveland, 2007) in the international human development scale. Arndt and Lewis (2000) project that the gross domestic product (GDP) in South Africa will be 17 per cent lower by 2010 than it would have been without AIDS. Non-income aspects of progress reflected in such human development indicators as life expectancy have shown significant declines due to civil wars, famine, economic depression, communicable diseases, and in particular the scourge of HIV and AIDS (Williams, 2003).

While most of the countries have programmes aimed at promoting human development, few have made any effort to mainstream older persons' development needs in the programmes – or indeed to recognise their capacity to contribute to and benefit from development initiatives. In Lesotho, a National Development Plan has been formulated in line with the United Nations Development Programme (UNDP), but a report (UNDP, 1998) shows that unemployment is estimated to be over 30 per cent; over 50 per cent of the population is poor, the majority of whom are older persons and reside in rural areas (UN, 2001b). Hence, one may conclude that for whatever reasons, implementation of the development plan has been unsatisfactory.

While national development plans and policies have been formulated in most sub-Saharan African countries, much remains to be done in incorporating older persons into the plans and policies, and removing constraints on implementation (UNFPA, 2002b). Inadequacies in the translation of development policies, strategic plans and programmes into implementable activities are contended to have contributed to poor human development in the sub-region (Dugbatey, 1999). Added to this difficulty are the negative effects of HIV and AIDS on human development in the sub-region (UNAIDS, 2004b). As part of a forward looking strategy on development and ageing in developing countries, the UNFPA consistently attempts to reorient and redirect thinking about individual and population ageing. Central to this approach is recognition given to opportunities for integrating ageing into a broad development framework, that takes account of individual development as a lifelong process, multi-generational relations, and a close link between ageing and development (UNFPA, 2002b). The UNFPA's approach to human development challenges stereotypes held in discussions on older people and development, such as that of elderly people typically viewed as a constraint on development (Blaikie, 1999). Such conclusions may be drawn too hastily. Benefits accrued in being old include a wealth of skills and experience – from the workplace,

public life and family (Stloukal, 2001). More recently, such skills are applied in caring for the ill and orphaned children.

3.4.3 HIV and AIDS responses and older persons' needs

For many countries in sub-Saharan Africa, HIV and AIDS and its consequences have emerged at a historic time of endemic poverty, under development, conflict and government under-spending on public health services. HIV and AIDS exacerbate the poverty, further undermine human development, increase the number of orphans, and contribute to stigma of and discrimination against infected and affected persons UNAIDS, 2004a). Hence, national responses to address the problems brought about by the epidemics need to pay specific attention to such issues. Previous sub-sections have looked at a variety of policy issues. This sub-section reviews national responses to HIV and AIDS and older persons' needs.

When AIDS first gained international attention in the early 1980s, the WHO took a lead in identifying it as a major health concern (Jackson, 2002). Many sub-Saharan African countries have been guided in the development of their policies and strategic plans in response to the epidemics by the WHO's Global Programme on AIDS. However, national responses in sub-Saharan Africa have varied owing to resource constraints and the extent of political will to address the epidemics, even where clear scientific evidence and advice exist (Jackson, 2002; UNAIDS, 2004a). Botswana has developed a comprehensive national policy and strategic plan on HIV and AIDS, which incorporates prevention measures, and was the first country in sub-Saharan Africa that aimed to provide anti-retroviral therapy to all its needy citizens. Sadly, the country's HIV prevalence rate of 24.1 per cent is the second highest in the world, after Swaziland (UNAIDS, 2007), which suggests poor implementation of the plan.

A slow response to formulate national HIV and AIDS related documents to combat the scourge in some sub-Saharan Africa countries has increased the burden of care. Namibia drafted several HIV and AIDS policies before one was finally adopted - in 2007 (Weidlich, 2007). Kenya, albeit with a low HIV prevalence of 7 per cent (Kenya National HIV/AIDS Strategic Plan, 2006-2010), has developed an HIV and AIDS strategic plan that targets specific social groups such as discordant couples, commercial sex workers, OVC and migrants, but excludes older persons - who are themselves at risk of infection with the virus (WHO, 2002a; UNAIDS, 2004a).

Some SSA countries, in early stages of their epidemic, introduced backward, discriminatory and restrictive legislation around HIV and AIDS, aimed at segregating PLWHA. In 1996, a Nigerian military administrator reportedly ordered the arrest and confinement of all AIDS patients in his state, in the belief that this would prevent the spread of HIV (Heywood, 1999). In Swaziland, which has the highest HIV prevalence globally, 38.8 per cent, a political leader who chaired the National Council on HIV and AIDS commented in favour of segregating people with HIV and AIDS (SANASO, 2001).

3.4.4 Responses to older persons' needs in the era of HIV and AIDS

In general, most policies on older persons cover their basic needs, to an extent, such as housing, social security and pension provision – be it private, public, contributory or non-contributory. More forward looking policies make a link with wider development issues and aim to integrate ageing into other national policies. In the SSA sub-region, a need to link provisions and policies on older people with issues such as HIV and AIDS, poverty reduction, human development has been recognised (HAI, 2002a). In 1999, HelpAge International reviewed the status of national policies on ageing in 46 countries and found that only 10 had one in place. Since then, ten years later, an additional six countries have formulated a national policy framework on older persons and others have incorporated provisions for older persons in sector-specific (e.g. health) policies (Aboderin & Ferreira, 2008). Among countries that have adopted a national policy on ageing are Mozambique, Tanzania, Mali, Egypt and Tunisia. However, a number of countries have only bills on ageing and others are taking their time in developing a policy. Cameroon, Kenya, Zimbabwe, Ghana, Uganda, Zambia and South Africa still only have policy documents in draft form (HAI, 2005b). Zimbabwe started a consultation process towards developing a policy in 1992 but stalled some years ago (HAI, 2005b).The slow pace of policy formulation, despite rapid population ageing, is worrisome (HAI, 2002a). The lack of a national, comprehensive policy to support older persons' needs in most SSA countries shows an apparent lack of urgency in this regard on the part of the governments, or a deprioritisation of older persons' needs.

While progress has been made in some SSA countries in the past decade or so in strengthening old age support through the introduction, or reform of social pension or social assistance programmes, the health care needs of older persons have received little policy attention and indeed little intervention (HAI, 2002b; Caldwell, 2001). Reasons for a relative

lack of attention paid to health care policy and provision for older persons include non-recognition of their special health care needs and a need for dedicated services; consequently, few dedicated health professionals have been trained (UNFPA, 2002a). Public policies and programmes are thus needed to address the needs of the older poor who cannot afford basic services such as health care.

3.4.5 Primary Health Care (PHC) national policy formulation and older persons' health care needs

The PHC systems of some sub-Saharan Africa countries are informative in respect of what can be achieved in addressing the health needs of older persons. Older persons already constitute a significant proportion of clientele at the lower levels of the PHC system; as the population structure ages, they will become more numerous and the prevalence of chronic disease will increase (WHO, 2004c). However, older persons typically encounter numerous barriers when they seek health care. Zimbabwe operates a decentralised PHC model, and achieved major improvements in child mortality rates and nutrition in the ten years after independence (WHO, 2002a; Sanders et al., 2005) as resources were redeployed from central and general hospitals to district hospitals and clinics. Now, PHC service centres in that country remain inaccessible to numerous older persons because of long distances and lack of money for transport. The same situation applies in most southern African countries. Numerous clinics have a shortage of drugs (HAI, 2002b; WHO, 2002a). In general there is little importance assigned to the health of older persons in these countries (WHO, 2002a).

Some of the countries have plans to show their commitment to PHC principles. Kenya's plans started in 1980-1984 and were followed up in 1989-1993 (WHO, 2003); however, the plans are reported to be of no benefit to older persons, many of whom resort to consulting traditional healers for health care because of the high cost of medical treatment (HelpAge Kenya, 2001; HAI, 2002b). Corruption and bribery, and failure to implement national laws entitling older persons to free medicines further diminish the accessibility of health services to older persons (HAI, 2003b). Health care staff members at PHC centres are reported to be uncommitted to treating older clients. When some older persons visit health care centres, they are told they have a disease called "old age" (HAI, 1999b; HAI, 2002a).

In efforts to monitor the performance of their PHC systems, some SSA countries such as Swaziland have developed strategies with sets of indicators to assess the health status of children and mothers, but not that of older persons (Swaziland Ministry of Health, 1983). Clearly, although PHC in SSA countries may appear promising on paper, it is not fully supportive of older persons' health needs. Even when services are available, health and welfare professionals have little knowledge or understanding of older persons' health problems, and ageist attitudes prevent them from rendering appropriate care (HAI, 2002a; Nhongo, 2003). Thus, it appears that implementation of PHC policy provisions is largely rhetorical when it comes to addressing older persons' health care needs. Against this background, I look specifically at the South African government's policy, strategic plans, programmes and legislation to address issues of human rights, human development, HIV and AIDS, older persons and Primary Health Care in the sections below.

3.5 SOUTH AFRICAN GOVERNMENT RESPONSES TO OLDER PERSONS' NEEDS

3.5.1 Human rights and older persons

Historically, the human rights of the majority of the South African population were undermined by injustices under successive colonial administrations, and more recently the four-decades long system of "separate development," or apartheid (from 1948 to 1993). Black older persons, in particular, endured abuse of their human rights through the entire four decades and more of apartheid, through inequitable access to political power, economic resources and general human development experienced by their white counterparts. As a result, they experience cumulative disadvantage in old age. With the advent of democracy in 1994, all South Africans' human rights were protected under the new Constitution (Act 108 of 1996). Chapter 1 of the Constitution highlights the fundamental principles upon which the democracy is premised, one of which is the protection of individuals' dignity. In conjunction with the Constitution's provisions is enabling legislation which further protects citizens' human rights (see Chapter 2 of this dissertation). Specifically, under Chapter 2 (Bill of Rights), section (9) (iii), it is stated that no one must be discriminated against based on his or her age. Hence, older persons are constitutionally ensured of a right to the same treatment as persons in other age groups.

In accordance with international charters, covenants and treaties on human rights, South Africa's constitution and bill of rights include political, civil, cultural and economic rights among other rights. The constitution is comprehensive in its address and defence of human rights of all South Africans. However, although it stipulates that no one will be discriminated on grounds of age, it does not openly advance the rights of older persons. As a result, it is found in practice that older persons are consistently passed over in the allocation of resources (*Cape Argus*, 2003). Anecdotal evidence in the media shows widespread abuse of older persons, where their rights are violated and they are inadequately protected under existing laws (Commission on Gender Equality (CGE), 2005). A study commissioned by the national health department, conducted by the Africa Strategic Research Corporation (1999), found that 53 per cent of older respondents had personal experience of abuse. As a consequence, the circumstances in which many older persons in South Africa find themselves infringe on their right to dignity (CGE, 2005). Nonetheless, specific new legislation now exists to protect older persons' rights: the *Older Persons' Act* No.13 of 2006. It remains to be seen however to what extent the legislation is applied to protect the human rights of older persons in practice. The following subsection deals with human development and older persons in South Africa.

3.5.2 Human development and older persons' development

Prior to 1994, the human development needs of the majority of the South African population were overlooked for decades. The majority of citizens were residentially restricted to poor and under developed rural areas, and had little access to opportunities for self advancement. Nevertheless, in comparison to the Human Development Index (HDI) for sub-Saharan Africa in the early 2000s (0.468), South Africa's HDI (0.684) was higher (NMG-Levy Consultants, 2002). However, in 2005 the country's HDI dropped to 0.674 (Human Development Report, 2007/08). The decline in HDI is said to be partly due to AIDS related mortality, which has reduced the life expectancy component of the HDI value. Coupled with the AIDS mortality effect was lower expenditure on public education (NMG-Levy Consultants, 2002). Encouragingly, the South African government increased its expenditure on health, from 3.1 per cent of Gross National Product in 1990 to 3.7 per cent in 2000 (Garbus, 2003).

Although older persons bear many of the effects of AIDS, their changing human development needs and contributions are routinely ignored (HAI, 1998). Their contributions in the era of

HIV and AIDS are overlooked, in spite of the wealth of experience that they bring to public and family life, and evidence of their contributions to development (HAI, 1998). In South Africa, age-based retirement is mandatory, usually at 60 years; certainly, economic activity is disallowed for social pensioners (see Chapter 2) if they are to remain eligible for a social grant. This requirement – mandatory aged-based retirement – contradicts calls on governments to share a commitment to international development targets, *inter alia*, by halving the number of people in extreme poverty by the year 2015 (MDGs, 2002), as it excludes older persons from the workforce (May, 2003). Nonetheless, South Africa is making progress in efforts to achieve the MDGs: it is certainly fighting poverty and has introduced universal primary education. A UNDP report shows that the income level of the poorest has increased as a result of the country's social security programme (Johansson, 2008).

3.5.3 Responses to older persons' needs

A range of policies, programmes and legislation has been available historically to address the socio-economic, health and well-being needs of older persons in South Africa. However, earlier legislation, policies and programmes were designed primarily to address the socio-economic and social needs of economically indigent white older persons (Sagner, 2000). The introduction of the social old age pension through the *Old Age Pension Act* of 1928 was discriminatory at the outset: it provided for pensions to be paid to white and coloured older persons and not Africans and Indians (Sagner, 2000). A rationale for the discrimination at the time was that the pension programme would encourage loyalty from the white working class towards the state and would help to integrate poor whites into the economy (Sagner 2000). Subsequent to the 1928 act, the Pension Laws Amendment Bill was passed in 1944, which extended the pension to all age-eligible South Africans, but remained discriminatory in terms of the amounts paid to beneficiaries in the different race groups (Tribe, 1976; Legido-Quigley, 2003). The amount of pension benefits received by whites was four times higher than that paid to blacks, with Indians and Coloureds falling in-between: a ratio of 4: 2:1 (Legido-Quigley, 2003).

When the Nationalist Party assumed power in 1948, its apartheid policy heralded the introduction of restrictive measures that led to a reduction in pension expenditure on blacks, by limiting the number of black beneficiaries (Sagner, 2000). Race segregated policies provided an overall framework for the development of successive social age pension

legislation, up until 1993. Nonetheless, by 1993, on the eve of democracy, parity was achieved in the amount of the pension paid to beneficiaries in the different race groups, through the *Social Assistance Act* No. 59 of 1992 (Lund, 1999). Currently, the *Social Act* No. 13 of 2004 provides the legislative framework under which the social assistance grant programme is operated.

The old age grant provides a significant source of income to beneficiaries. It has a high take-up rate, especially in rural areas (Liebenberg & Tilley, 1998), and is seemingly well targeted to older persons (Case, 2001). The amount of the pension has been increased annually, in line with inflation; but numerous beneficiaries complain that the amount is not commensurate with escalating needs, especially those of beneficiaries burdened with the effects of HIV and AIDS, whose families and households make specific demands on their pension income (Ferreira, 1999).

Other legislation has also been available to address the needs of older persons historically. The *Aged Persons Act* No. 81 of 1967 provided for the protection and welfare of certain older and debilitated persons, the care of their interests, and the establishment of institutions to care for them. The act did not deviate from previous segregationist policy and legislation: in truth, it provided primarily for the white older population. Only a few residential care facilities, for example, were available for black older persons. However, the act was amended a number of times prior to 1994, in order to remove certain discriminatory provisions. These amendments culminated in the *Aged Persons Amendment Act* No.100 of 1998 (National Report on the status of older persons, 1994-2002). Nonetheless, the 1998 act continued to focus on residential care facilities, which accommodated a disproportionate number of white residents.

Then, new legislation was developed, over a protracted period, and a new act, the *Older Persons Act* No.13 of 2006, was finally adopted. Core objectives of the new act deal with issues relating to i) the protection of older persons' rights - as entrenched in the South African Constitution, including maintaining and protecting their rights as recipients of services; ii) combating elder abuse, and maintaining and promoting older persons' status, safety, security and dignity; and iii) the regulation and registration of residential care facilities. The protection of older persons' rights, as provided for in the act, supplements their rights protected under section 9 in the Bill of Rights of the Constitution of South Africa.

A particular strength of the act, relevant to this dissertation, is its acknowledgement of the right of older persons to receive information, education and counselling services on HIV and AIDS and on care for orphans. Moreover, the act promotes the provision of nutritionally balanced meals and medical care to needy older persons. In practice, several of the provisions, such as older persons' entitlement to dedicated medical care (e.g. geriatrics), are not being implemented, or at least not satisfactorily (see Benatar, 2004). The act makes no mention of the vulnerability of HIV infected older persons, nor the special support needs of these persons. More critically, it makes no provision for sustaining older persons' health so that they may continue to render care and support affected family members. The act merely represents the specific areas of responsibility that the Department of Social Development (DoSD) sees as its mandate; it does not cover the health, housing, transport, justice and other sectors, under which the rights, care and support needs of older persons fall equally. The legislation is therefore deficient in that it is not comprehensive.

The sectoral divide between the government ministries of social development and health continue to militate against integrated and comprehensive formal responses to the problems of older persons such as elder abuse (Ferreira & Lindgren, 2008). The *Aged Person Amendment Act* 100 of 1998 which provides among other things for "…the protection and welfare of older persons in certain institutions, for the accommodation and care of such persons in such institutions, for the payment of certain other allowances (subsidies) to meet older persons' needs…". Again, the act covers only the range of services provided by the social development ministry under its mandate (Ferreira & Lindgren, 2008). Provisions in the act cover, *inter alia*, the promotion and protection of older person's rights and the provision of programmes including community services for frail and homebound individuals.

There appears to be little harmonisation of programmes for older persons in South Africa, which continue to be operated independently, even within the same ministry. Little dialogue appears to take place between the social development and social security directorates within the Department of Social Development, and between this ministry and the health ministry regarding policy, programmes and services for older persons. This situation contradicts the stated mission of the DoSD, which it states is "to ensure the provision of comprehensive social protection services against vulnerability and poverty within the Constitutional and legislative framework, and to create an enabling environment … "(DoSD profile booklet, n.d.:1). Hence, what is lacking is a comprehensive approach to older persons' needs, to

ensure their well-being and inclusion in development initiatives. Thus, the development of a cross-cutting policy framework, possibly based within the DoSD, may be considered towards forging the co-ordination and monitoring of the development and implementation of interventions to meet older persons' needs.

3.5.4 Ministry of Health responses to older persons' needs

The health ministry has no dedicated policy pertaining to older persons; only a *National Health Act* (No. 61 of 2003). The legislation replaced the *Health Act* No. 63 of 1977. The new act provides a framework for legislation: it sets out broad legal and operational principles that are fleshed out in regulations. Some of the major principles of the new act are to establish a uniform health system; to restore dignity to citizens, and to provide free health care to those who cannot afford it. However, the act does not mention nor does it address the health needs of older persons. In general, the delivery of health services, as provided for in the act and policy, is guided by the philosophy of Primary Health Care (PHC) (see Chapter 2).

A key achievement of progressive implementation of PHC policy in South Africa is that people have far easier access to basic health care, owing to the removal of fees for services for certain vulnerable groups such as children under six years and pregnant women, among other measures. However, a move away from a hospital based system to a primary health care system has brought both achievements and problems, especially regarding provision of health care to older persons. Although older persons who are social pension beneficiaries are entitled to free health care at public health sector facilities (Ferreira & Kalula, 2007.), services such as geriatric clinics and community nursing at primary level were closed down after 1994 (see Benatar, 2004). The country has only eight registered geriatricians, who work at a tertiary level, to serve a population of 3.3 million persons age 60 years and over (Ferreira et al., 2007). Geriatrics is hardly included in the teaching curricula of any of the medical schools in South Africa. Ironically, the shift to PHC has neither eased the burden on hospitals at secondary level. Instead, admissions have increased phenomenally, by about 100 000 a year since 1994, mainly as a result of AIDS among other health problems (Department of Health, 2002).

Other ministries may have single mechanisms to address the needs of older persons. In 1998 the Transport Department launched its *Moving South Africa Strategy*, which represents a unique strategic framework for the improvement of passenger transport over a 20-year period. The new transport system is also directed specifically to historically disadvantaged people, among whom are elderly persons (South African Consulate, n.d.). The ministry has also developed and released a Transport Sector Strategic Plan on HIV and AIDS, the overarching objective of which is to "establish and maintain a healthy community and stable transportation sector by preventing and managing HIV and AIDS," but the plan does not mention older persons and their needs as a vulnerable group. Likewise, the housing ministry, a vital ministry in servicing the housing needs of older persons - especially the frail, developed a New Housing Policy and Strategy for South Africa in 1994, which has an all inclusive approach, critical for the sustainability and legitimacy of the housing delivery process. The policy specifically mentions special needs of certain groups in society such as the youth, disabled people and the elderly (New Housing Policy and Strategy for SA, 1994). A housing subsidy scheme established by the government makes special provision for older persons who are recipients of the OAP (New Housing Policy and Strategy for SA, 1994). However, implementation of policies of the two ministries to benefit older persons has been ineffectual. The majority of needy older persons are neither aware nor informed of the existence of such a scheme designed and operated to benefit them.

3.5.5 Ministerial responses to older persons affected by HIV and AIDS

Although AIDS is a major killer in South Africa (close to 336, 000 deaths in 2005 were associated with AIDS (MRC, 2006), the country has no national policy on HIV and AIDS that addresses the effects of the epidemics on older persons. The new National Strategic Plan (NSP, 2007-2011) makes no mention of older persons. No ministerial policies exist either on HIV and AIDS to address the effects of the epidemics on older persons *per se*. Only the Ministry of Social Development has developed a response, but which merely comprises interventions or programmes, such as strengthening home and community based care and support, incorporating gender and HIV and AIDS into all programmes, and providing support to orphaned and vulnerable children. The response makes no mention of older persons who care for persons infected with or affected by HIV and AIDS.

In 1992, at the time that the National Party government was gradually relinquishing power, a National AIDS Convention of South Africa (NACOSA) was convened, which brought together the African National Congress (ANC), the ANC-aligned United Democratic Front (UDF), and the National Party government's ministry of health to develop a comprehensive 1994 national AIDS plan. The plan estimated that by 2000, there would be between four and seven million HIV positive cases, with about 60 per cent of total deaths due to AIDS, if HIV prevention and control measures were not in place. In response, a National Strategic Plan (NSP) on HIV and AIDS (2000-2005) was developed. The NSP 2000-2005 emanated from the Operational Plan for Comprehensive HIV and AIDS Care, Management and Care 2003, and various programmes of the plan have guided the management of the epidemics in South Africa. However, the Operational Plan and both the old NSP 2000-2005 and the new NSP 2007-2011 strategic plans make no mention of older persons, either as infected or affected persons.

A review of national responses to the epidemics in South Africa shows sector specific policies relating to health, education, transport and housing. Beside these policies, are youth (18-35 years) oriented HIV/AIDS and STI programmes: e.g. voluntary counselling and testing (VCT) programmes, contraceptive programmes such as condom distribution, post exposure prophylaxis (PEP) programmes and syndromic management of sexually transmitted infections (STIs) programmes. A focus of the policies and programmes has been overwhelmingly on affected and infected children, and how to provide for future orphans as a result of AIDS (DoSD Strategic Plan, 2006/7-2009/10). Mention is made only in passing in some of the government ministries' legislation to older persons' situation, and then only in terms of the roles they assume as caregivers – to both adult children, and sick, vulnerable and/or orphaned grandchildren. Very little provision, if any, has been made in past and present national strategic plans (NSPs) and programmes for the support of older caregivers (NSP, 2005-07/2007-11) – either through information and education, in their roles as caregivers, or in their loss of support structures as their adult children succumb to the disease.

Nonetheless, the national education department's adult basic education and training (ABET) policy covers lifelong learning needs of adult persons, such as information and knowledge transfer on pressing national matters such as HIV and AIDS. In addition, the department has introduced a national law on HIV and AIDS, the *HIV and AIDS Act* No. 27 of 1996, for learners and educators in public schools, and students and educators in further education and

training institutions. Section 9.4 of the act acknowledges the valuable role played by grandparents and caregivers, and encourages their participation in the implementation of the policy, e.g. in parental guidance sessions. It also aims to make them aware of their role as sex educators and imparters of values at home.

On the other hand very little attention has been given in policies, even if noted in passing, to the significant contribution that older persons make in AIDS households towards sustaining the family unit and maintaining a family environment in which grandchildren without their parents may be nurtured and grow up (HAI, 2003a; Ferreira, 2006). South Africa's national policy response to the epidemics has not been different to that of other sub-Saharan African countries, in as far as including the needs of older persons, who are a care resource, is concerned.

According to South Africa's Constitution (1996), the country's citizens have the right to health care services under its Bill of Rights. Section 27(2) puts the onus on government to achieve the full realisation of this right. Therefore, by implication the government is constitutionally obligated and expected to implement a policy to address the HIV and AIDS epidemic. The South African HIV and AIDS strategic plans 2000-2005 and 2007-2011 are well developed documents. However, obstacles to implementation of what is on paper, are the contradictory or evasive public statements made by the country's President and the Minister of Health.

Most controversial has been former President Mbeki's challenge of the scientifically established causal link between the HI virus and AIDS (Swan, 2001; Mbali, 2002), and the scientifically proven effectiveness of anti-retroviral drugs in the management of AIDS, which the former health minister alleged are toxic and "kill." The negative media publicity of these recent controversial stances did grave damage to the credibility of the government and its policy response to HIV and AIDS. The resistance of the health minister to providing ARVs to prevent mother to child transmission (MTCT) of HIV, as well as her persistent emphasis on "nutrition" above ARV therapy (Geffen, 2006), further discredited the government's response to the epidemic. Although the government announced it would roll out ART at state facilities to prevent MTCT, it fought the national Treatment Action Campaign (TAC) and South African Medical Association (SAMA) in a constitutional court case, arguing that it is not constitutionally obliged to provide "toxic" ART. The ruling of the court was in favour of the

TAC and SAMA, and the South African government was ordered to provide treatment at public health care facilities (Moderator, 2008).

The disjuncture between what the government policy documents on the epidemics state and the utterances and actions of officials has caused uncertainty amongst health service providers and retarded progress in the fight against the disease. Caution among health service providers in public health establishments when treating PLWHA has been the order of the day (Smith, 2002), as the providers felt they were hamstrung and were afraid to contradict government rules. For example, when a medical doctor allowed a non-profit organisation to provide ARVs to rape survivors, the provincial health department applied stiff sanctions by suspending the official on grounds of misconduct and ultimately firing the official (Smith, 2002). With the later withdrawal of President Mbeki from the HIV and AIDS public debate, and his deputy-president's assumption of leadership against the epidemic, urgency in dealing with it was restored.

What is seemingly missing in government responses to the epidemic is the provision of tools to co-ordinate and integrate various ministerial responses. These responses include the co-ordination and implementation of different sectoral policies, strategic plans, programmes and legislation in a comprehensive response from government to older persons' support needs. The fragmented response and a lack of integration of older persons in the response to the epidemics remain an omission sorely in need of redress.

3.6 COMMUNITY RESPONSES TO HIV AND AIDS AND OLDER PERSONS IN SOUTH AFRICA

Despite the availability of a number of interventions for the management of the epidemics in South Africa by government ministries, implementation of programmes has been largely left to the non-profit organisation (NPO) sector. NPOs have interpreted their role in this regard as a link between hospital based care and home based care. In the majority of cases, where their credentials are approved – in accordance with the *Non Profit Organisation Act* No.71 of 1997, NPOs are permitted by law to carry out services in communities. The NPO Act mandates the Department of Social Development to contribute towards the creation of an enabling environment within which NPOs can operate and flourish. NPOs may be subsidised through allocations from government, but are expected to submit annual reports, showing a

history of good community service delivery and accessibility and affordability of the services. However, most NPOs are also reliant on funds generated externally, e.g. from the European Union, to support their operations (Peltzer et al., n.d.).

NPOs that serve and support older carers typically aim to empower them by working with them (as opposed to working for them) – for example, by engaging them in income generating projects, imparting life skills, educating them on their rights and how to exercise those rights, and educating them about HIV and AIDS. In addition, NPOs typically offer older carers useful skills training and knowledge needed to manage a PLWHA and OVC. They also offer them respite from the demands and routine nature of caregiving, by providing emotional and nutritional support, and practical advice on matters relating to caregiving (see Chapter 2). In this regard they honour and respect the rights that older persons have under the International Human Rights Declaration of 1948 - for example, the right to access to information and education.

3.6.1 Difficulties for NPOs to implement international instrument provisions

Non-profit organisations that provide support to households affected by HIV and AIDS rely largely on government and international donor agencies such as the Global AIDS Fund, ActionAid, European Union (EU), Oxfam and HelpAge International for information and financial support to sustain their operations and programmes (Jackson, 2002; Peltzer et al., n.d.). The NPOs are typically contracted by the government to deliver services at a community level. They tender to deliver specified services in a response to a call for tenders in the Government Gazette. If their tender is successful, they enter into contracts which stipulate the terms of reference and expected outcomes. The government provides funding and monitors the NPO's activities aimed at achieving agreed objectives within agreed time cycles.

Governments generally lack capacity to render community services, and as NPOs are knowledgeable about the support needs of the PLWHA and caregivers they work among, the government relies on them to provide the services. This reliance is particularly strong where responses are required to meet the needs of persons infected with HIV or affected by AIDS (Jackson, 2002). However, some researchers have pointed out that state agencies find it difficult to work with NPOs because of the NPOs' limited managerial capacity, and inability

to meet rigid agency accountability guidelines and costing such as in audited financial reports (Lenton et al., 2003; Mpanju-Shumbusho, 2003). In addition to partnership difficulties, NPOs tend to compete with one another for funds and credibility within the communities they serve, rather than forge alliances within the non-profit organization fraternity (International AIDS Alliance, 2002; Jackson, 2002) and rationalise employment of scarce resources. Another obstacle to the contributions that NPOs are able to make is low coverage. Drew and colleagues (1997) estimated that most home care programmes attain only about 1-2 per cent community coverage, and have poor referral of patients to other levels of care, because they are not well recognised, for example, by welfare workers or health care providers (Jackson, 2002; Akintola, 2004).

Non-profit organisations typically experience difficulty in obtaining funds from donor agencies. They will draft a funding proposal and submit it to an agency; the proposal will be assessed and approved for funding if it meets the agency's funding criteria. However, donor agencies often have inordinately complex application procedures and stringent requirements that are incompatible with the capacity and scope of NPOs (Jackson, 2002; Save the Children, 2005). An end result is that many NPOs are poorly managed, are unsustainable and are forced to close down.

Several studies have demonstrated NPOs' valuable involvement with PLWHA and their caregivers in AIDS care, treatment, literacy and education activities, and have noted the ability of the NPO personnel to anticipate the health and material needs of the community (Gilks et al., 1998; Blinkhoff et al., 1999; Oleja, 1999; Birdsall & Kelly, 2005). NPOs also provide non-formal education and raise awareness through less costly techniques such as songs, storytelling, community theatre and or drama - as a means of health education that is culturally acceptable to and effective in the community (WHO, 1978; Shaik & Hatcher, 2004). Non-formal methods of active learning are thus compatible with the general principles of Primary Health Care, such as community participation and appropriate techniques to deliver health messages (WHO, 1978).

3.7 SUMMARY OF THE REVIEW

The review of relevant instruments, legislation, policies and programmes covered the situation in several SSA countries, but focused largely on situations in South Africa. It was neither feasible nor indicated to attempt a fuller review of policies, strategic plans, programmes and legislation in regional countries in this chapter. The global and regional instruments and documents reviewed all highlight an acknowledgement of the burden of HIV and AIDS related caregiving on older persons in the 21st century - particularly in SSA. Gaps in and shortcomings of multi-sectoral responses to the effects of the epidemics at a national level have been identified, which relate specifically to the co-ordination, consultation and involvement of older persons. The identification of such gaps and shortcomings will serve to inform the development of a policy framework for addressing the needs of older persons affected by HIV and AIDS later in this dissertation.

3.7.1 International response frameworks

International instruments such as the Madrid International Plan of Action on Ageing (UN, 2002b) acknowledge the challenges faced by numerous older persons, especially in developing countries, and urge governments to introduce policies that make provision for in-kind support, health care and loans to older caregivers to assist them in meeting their household needs. These recommendations call for governments to do more than what they do at present, given the added problems that many older persons currently face, such as caring for sick adult children and OVC as a result of AIDS. Although the South African government is a signatory to MIPAA, it has thus far not taken steps to ensure that AIDS treatment and support strategies and programmes address the needs of older persons affected by the disease. On the other hand several NPOs have designed and implemented programmes and interventions to support these persons. Nonetheless, review and appraisal of progress in the implementation of MIPAA globally is under way at present (Sidorenko, 2004) and outcomes of the review may indicate the stage of progress in this regard in SSA countries. Similarly, recommendations in the AU Policy Framework and Plan of Action on Ageing (AU, 2003), to which the South African government is also a signatory, such as ensuring that older persons' needs and rights are integrated in all existing and new policies in all sectors, has not been realised. In short: older persons' needs, especially relating to HIV and AIDS, are not being addressed adequately, if indeed at all, in any policy sector in South Africa.

3.7.2 Regional and national responses

Regional instruments such as the African Consensus and Plan of Action to Overcome HIV and AIDS (Africa Policy E-Journal; 2000), and the AU Policy Framework and Plan of Action on Ageing (AU, 2003) provide concrete steps to be taken to support older caregivers. Among the steps recommended are the provision of support for caregivers and opportunities for older persons' participation in development initiatives, to enable them to become full allies in the fight against the epidemics. Most countries in the sub-region (SSA) have developed policies or strategic plans in response to the epidemics. Some countries that have shown the political will to fight the epidemics, such as Uganda, have managed to turn their country's epidemic around. However, the majority of the policies or strategic plans do not include older persons or their representative organisations as important role players in the fight. There is neither any evidence to indicate that the commitments made in the documents have been implemented in the majority of the countries, including South Africa.

3.7.3 South African government responses

The review has highlighted a lack of, or ineffective responses to the support needs of affected older caregivers in South Africa. Multi-sectoral responses have been lacking, in particular, through a lack of co-ordination of response programmes of the health and social development ministries, and older persons' non-integration in programmes. Ferreira and Lindgren (2008: 91) have pointed to fragmentation in sectoral policies and programmes: "[while]…the social development ministry is tasked with the subsidization of frail care, which is primarily a health matter; nursing regulations are determined by the health ministry, while monitoring of facilities should be done jointly." A lack of consultation with older persons, or at least organisational representation of their interests in the development of critical instruments such as the national strategic plan on HIV and AIDS, is another key gap in the formulation of national responses to older persons' support needs.

A failure to co-ordinate HIV and AIDS responses within a well developed policy framework will continue to cause older caregivers' issues to be overlooked in policy responses. Joubert and colleagues (2002) note that this oversight constitute(s) an undermining of older persons' human rights. Thus, a policy framework that provides for the inclusion of a range of role players, from government, non-profit organisations, religious bodies and business, can

provide for the development of an appropriate, integrated comprehensive response to older carers' needs.

Provision of support to meet older carers needs, needs to incorporate an element of Primary Health Care: that of advancing health and well-being into old age. The World Health Organization's active ageing policy framework (WHO, 2002c) calls for the development of health care systems that are responsive to the needs of ageing populations. Such systems should be aimed at enhancing the capacity of the primary health-care sector to respond to older persons' health care needs at a local level and to do so appropriately. The Madrid Plan (UN, 2002b) recommends that health care services include special training of health personnel and that facilities meet the special and specific health care needs of the older population, such as the management of chronic illnesses.

South Africa's public health system is under severe strain to meet multiple demands made on its limited resources. A myriad of obstacles limit equitable provision of health care to older persons, such as limited staff trained in geriatric care, the brain drain of qualified and specialist staff, a shortage of drugs and industrial action by health care providers. Therefore, although government ministries have formulated progressive policies and legislation to meet older persons' needs, the task now is the implementation of the provisions through programmes to a satisfactory level.

Finally, some progress has been made in South Africa in reforming legislation, such as the *Older Persons' Act*. The new legislation is designed to address the needs of all older persons equitably. Such progress has been achieved since 1994, through the new political dispensation, directed in particular at closing disparities in social security (OAP) among older persons. However, much more remains to be done in involving older persons in the formulation of formal responses to their needs in general. Indeed, a main obstacle to the implementation of the provisions of international instruments, and the formulation of national policies and strategic plans is the fact that financial resources are required that the government may lack, forcing it to be selective in the allocation of its limited resources.

3.8 TOWARDS AN APPROPRIATE POLICY FRAMEWORK

A number of international, regional and national instruments are thus available to guide the development and implementation of policy and programmatic responses to the needs of older persons affected by HIV and AIDS, but numerous gaps remain in national policies that mitigate against a comprehensive and inclusive response. Mechanisms and frameworks are needed to address the gaps in order to benefit of older persons. The construction of an evidence based policy framework will be a valuable contribution in this regard. Such a framework should provide for: i) The involvement of older persons or their representative organisations in the design of responses; ii) the co-ordination of responses of different government departments, iii) sensitivity to the gendered nature of caregiving; iv) acknowledgement of disparities in socio-economic status and difficulties of caregiving for older carers in rural and urban settings; v) meeting the health care needs of older carers themselves; vi) training health care personnel in the health care needs of older clients at district level; and vii) taking cognisance of older persons' rights as caregivers and integrating their contributions in the development of interventions. In this dissertation, I attempt to bridge such gaps by developing a policy framework that is informed by evidence from an empirical study to be conducted. The framework will lie at the intersection of various socio-economic, development and health care needs of affected older persons. Such a policy framework may serve to bridge and fill gaps in future policy development, and to inform policy and programme development and implementation.

CHAPTER FOUR: RESEARCH METHODOLOGY

4.1 INTRODUCTION

The research design and research methods used in the empirical study are described in this chapter. A mixed-methods approach was employed, which included quantitative and qualitative research techniques. Both methodologies have particular strengths and weaknesses, but when used together, the weaknesses of one method could be mitigated by the strengths of the other. Quantitative and qualitative research techniques can thus be employed compatibly in the same study (Patton, 1990; Newman & Benz, 1998). Given the nature of the research questions of the empirical study in this thesis, the employment of a single quantitative or qualitative data collection technique on its own would not have enabled me to capture the complex and multiple dimensions of the impact of HIV and AIDS on older persons' households and older carers. Thus, the employment of a mixed-methods approach, in which the two research methods were combined, was indicated and constituted an innovative research approach in this problem area.

4.1.1 Quantitative and qualitative research

4.1.1.1 *Quantitative research methods*

Quantitative research typically involves numerous variables and treatments, such as factorial designs and repeated measure designs. The designs can involve elaborate structural equation models that incorporate causal paths and the identification of the collective strength of multiple variables (Creswell, 2003). A single quantitative enquiry technique, however, is to be employed in the present study, namely a survey. A survey is typically a cross-sectional (but may be a longitudinal) data collection technique in which a pre-constructed questionnaire is used in structured interviews to collect data. The quantitative nature of a survey is generally reliant on the recruitment of a representative sample of the population of interest. The requirement of a randomly selected sample is to be able to generalise findings from the sample to the study population, so that inferences may be made about certain characteristics, attitudes, and/or behaviour of the population of interest (Babbie, 1990; Fowler, 2002).

Fink (1995) identifies four types of quantitative survey: i) Self-administered questionnaire; ii) face to face interviews; iii) structured record reviews – to collect financial, medical, or school information; and iv) structured observations. In addition, web-based or internet and telephone surveys may be employed as a survey data collection technique (Nesbary, 2000). In the present study, the data will be collected at a single point in time (the study design is thus cross-sectional), using a pre-constructed questionnaire administered in face-to-face interviews.

Quantitative data are measurable units of information, and are amenable to statistical manipulation through the application of different scientific techniques. A main purpose of quantitative data is to define and measure the magnitude of the problem under investigation. However, the data are limited in that they do not describe or capture human aspects of the problem, such as actors' perceptions, feelings and views (Creswell, 2003).

Hence, a limitation of quantitative research methodology, and the use of a survey technique in the present survey, is that the data collected do not allow sufficiently for understanding complex issues – such as the effects of HIV and AIDS on older carers, and neither have the flexibility to explore sensitive issues (Griffin, 1986; Schoepf, 1991). To compensate for this weakness, as will be done in the present study, qualitative research techniques may be used in conjunction with, and complementary to a quantitative research technique – in the present case, a survey.

4.1.1.2 *Qualitative research methods*

Qualitative research techniques are mainly used for exploratory purposes, typically to explore a topic when little is known about the variables and theory base. Morse (1991:120) suggests that:

Characteristics of a qualitative research problem are: (i) the concept is 'immature' due to a conspicuous lack of theory and previous research; (ii) a notion that the available theory may be inaccurate, inappropriate, incorrect, or biased; (iii) a need exists to explore and describe the phenomena and to develop theory; or (iv) the nature of the phenomenon may not be suited to quantitative measures.

Different techniques are employed in a qualitative research approach to understand a phenomenon. In this study, the qualitative techniques used were case studies and key informant interviews. *Case studies* are used where a researcher explores an event, a process, or one or more individuals in-depth over a period of time; the researcher collects detailed information using a variety of qualitative data collection techniques (Stakes, 1995). The key informants technique involved obtaining information from knowledgeable persons for example NPO managers and government officials. In the present study, unstructured in-depth interviews were conducted with purposive samples of older respondents, and government and NPO representatives. The interviews with the older respondents were written up as case studies.

Unstructured interviewing, as a qualitative research technique, is well suited to the identification and description of experiential issues and daily activities (Gergen, 1988; Mitchell & Jolly, 1996; Hudelson, 1996; Mayan, 2001; Creswell, 2003). The technique is premised on an understanding that respondents are not mere objects to be counted, or having measurable characteristics, but rather are human beings who are in constant interaction with their environment and make sense of their experiences in that environment. Bowling (1997) suggests that such techniques are better able to provide insight into complex issues, and are more useful in studying new topics – or exploring topics on which little is known, than quantitative research techniques.

Qualitative data typically have a richness and a complexity that are lacking in quantitative data. Indeed, qualitative research approaches, and the data they elicit, are less bounded by a researcher's assumptions, and are more likely to be sensitive to unexpected findings (House, 1994). Probability statistics, derived through quantitative research, are numerous on a number of social issues, including health – for instance, but tell nothing about the experience of the subjects that make up the numbers; thus, only a fragment of knowledge is achieved.

Qualitative research has limitations, however. One limitation is a dependence on a conceptual framework to guide the inquiry on the issues to be examined. A qualitative study needs to indicate moreover how or where a researcher positions him-/herself; biases in the investigation and the data collected may stem from the researcher's social class or cultural position (Creswell, 2003; Miles & Huberman, 1984; Strauss, 1987). An additional concern – certainly for quantitative research oriented investigators, may be a lack of systematic

procedure, and problems of reliability and validity, as no tests are carried out on qualitative research data. (Mcqueen, 1992; Hardon. et al., 1995; Baum & Nesselhof, 1998). However, in their own right, qualitative data offer an appropriate source for deriving meaningful interpretations of subjects' experience (Hudelson, 1996; Schurink, 1998; Mayan, 2001).

4.1.1.3 *A mixed-methods approach*

Given the limitations of both quantitative and qualitative research methods, when used on their own, for achieving an in-depth understanding of a complex phenomenon, a decision was taken in the present study to employ a mixed-methods approach. The approach, which uses a combination of qualitative and quantitative methods to investigate a problem, would provide for a validation of the data, and findings of the analyses of the data elicited through the employment of multiple techniques. Qualitative and quantitative research methods are located at opposite ends of a continuum of methodological approaches, and each has its own principles and assumptions. The advantages and disadvantages in the use of a particular technique – and a particular approach – in the study were weighed in terms of the study's objectives. The employment of a mixed-methods approach would thus help to compensate for the weaknesses of a particular technique with the strengths of another (Creswell, 2003), and so strengthen the study findings and provide an improved understanding of the problem overall.

Nonetheless, the logic of incorporating qualitative research in the research design of the present study was to gain an understanding of caregiving and the support needs of older caregivers specifically. The qualitative methods would allow the researcher to probe the respondents' responses, and would facilitate the collection of narratives about the respondents' needs, experiences, of caregiving and knowledge and beliefs about HIV and AIDS. Unstructured questions would encourage a conversational approach in the interviews – although focused on a specific set of issues. The data elicited through the employment of the multiple techniques would later be triangulated, which would further help to offset inherent weaknesses of the methods and help to correlate the findings. Triangulation is discussed more fully later.

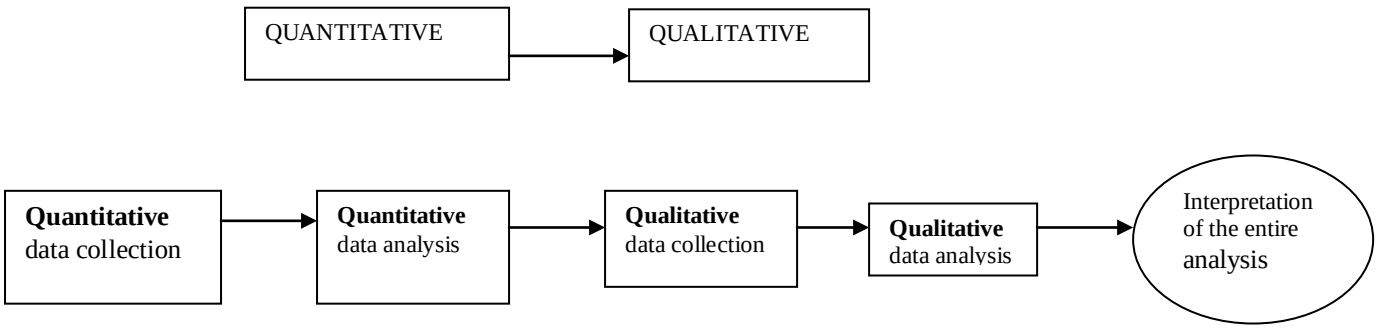
4.2 RESEARCH DESIGN

The research design employed in the present study is described below. No single research design can be identified as the most appropriate design for investigations of the problem of HIV and AIDS and its effects on older carers (see e.g. Fisher & Foreit, 2002). Nor is the employment of a particular research method, or the use of a particular research design of concern in this study, but rather how to collect data most effectively to serve and meet the study's objectives. The research design needed to be "exploratory-descriptive," and a decision was taken to employ a cross-sectional survey technique in conjunction with case studies and key informant interviews. The data from all sources were then triangulated.

A mixed-methods approach was used in the study. The approach helped the researcher to quantify the extent of the problem (older caregivers' experiences) and provided simultaneously for an understanding of the human experience in this case. The use of multiple methods, or the employment of several data collection techniques thus provided a comprehensive view and understanding of the older carers' situations and experiences.

The specific design approach employed in the study is referred to as a sequential procedure design (Creswell, 2003), and is shown graphically below. When carried out, the procedure enables the researcher to confirm, cross-validate and corroborate findings within a single study (Creswell, 2003; Poundstone et al., 2004). (See Figure 4.1.)

Figure 4.1: Sequential triangulation design



Source**:** Adapted from Creswell, 2003.

4.2.1 The survey

Kerlinger (1964) suggests that survey research is characterised by the collection of data from a sample of a population of interest, to assess the relative prevalence, distribution and interrelationships of naturally occurring phenomena in that population. Bryman (1989:104) argues for a formal definition of a survey, as "…entail[ing] the collection of data on a number of units and usually at a single juncture in time, with a view to collecting systematically a body quantifiable data in respect of a number of variables which are then examined to discern patterns of association." Bryman's emphasis is on survey research being conducted to provide a quantitative description of the individuals or other units concerned in a study. His emphasis on the quantification of variables and on sampling from known populations shows how survey researchers may share a similar scientific view of the nature of the research task from that adopted by researchers using qualitative research. Bryman's definition is applied in this thesis, for the empirical study, but the survey data are later complemented with qualitative research data.

4.2.1.1 *The study population*

The study population for the study consisted of all older persons (male and female) age 50 years and over who cared for adult children living with HIV and AIDS and grandchildren (who might or might not have been infected with the virus), who lived in households in urban settings or non-urban settings in three provinces of South Africa: the Eastern Cape (EC), Kwa-Zulu Natal (KZN) and the Western Cape (WC). The households appeared on the lists of clients of non-profit organisations (NPOs) – NGOs, CBOs and FBOs - that supported households in those areas. A database of NPOs in the provinces was obtained from the provincial departments of Health and/or Social Development.

The areas were delimited according to Statistics South Africa (Stats SA, 2001) census enumerator areas. The three provinces were selected due to the high prevalence of HIV infection in KwaZulu-Natal; the relative poverty and deprivation in the Eastern Cape – with an economic growth rate of 1.2 per cent; and the relatively strong economic growth rate of 4.6 per cent and the extent of established health services in the Western Cape (Stats SA, 2004). In the Department of Health's ante-natal seroprevalence survey, KZN was recorded as having the highest prevalence rate of HIV infection (37.5 %) (Makubalo et al., 2004).

A lower cut-off age of 50 years was set for the study, in line with the World Health Organization's Minimum Data Set on Ageing and Older Persons in sub-Saharan Africa (Ferreira & Kowal, 2006), rather than the internationally applied lower cut-off age of 60 years (UN, 2007). Justification for lowering the cut-off age was based on three considerations: i) Persons in the 50–59 year age group will be the next generation of older persons, and future resource requirements for planning purposes may be estimated from the number and situation of affected persons in this age category. Such estimates would include a projected demand for social security, health care and institutional care. ii) Within the African context, persons falling in this age category are traditionally regarded as old and responded to accordingly (WHO, 2001). iii) Research on older carers to PLWHA and OVC conducted by Ferreira et al. (2001) in the Western Cape Province found a need to lower the cut-off age to 50 years in order to recruit a sufficiently large sample of carers.

4.2.1.2 *The survey sampling procedure*

The sampling unit was a household in which an older carer co-resided with PLWHA and/or OVC. A sample size of 240 such households was determined, drawn from the three provinces, intended to be divided equally between urban and non-urban areas. However, it was not possible to recruit equal numbers of participants in urban and non-urban areas, as some sampled households did not meet the sample's inclusion criteria.

This figure was decided upon due to resource and time constraints, and on the basis that the extent of caregiving by older persons is unknown in the three provinces and in South Africa as a whole. However, a prevalence of 50 per cent caregiving among the respondents was assumed and a sample size of 305 subjects was accepted for the study which would allow a detection of 8 per cent change in the caregiving (at 80 per cent power and 5 per cent level of significance). The sample size was therefore increased from 240 to 305 to accommodate a 10 per cent refusal rate.

A multilevel sampling technique was used to draw a sample from the lists of NPO client households. The number of NPOs providing services to affected households identified in the delineated study sites in the three provinces were as follows: Eastern Cape: 131; Kwa-Zulu-Natal: 106; and Western Cape: 38. It was estimated that each NPO cares for between 100 and 450 households. The services they provide include imparting HIV and AIDS information and

education, developing income generation opportunities, addressing human rights issues, and counseling clients. Information on the exact proportion of households benefiting from the NPO services could not be obtained.

Nonetheless, an estimate of the relative proportions of older persons in the three provinces was gauged as follows: A household survey conducted in 2007 by STATSSA showed that 38.2 per cent of all old age grants were paid to beneficiaries in the Eastern Cape, with 46.4 per cent in KwaZulu-Natal and 15.3 per cent in the Western Cape (STATSSA, 2007). These beneficiaries would receive free primary health care at specific levels of the public health system, such as the district level.

A database of all registered NPOs in the country was obtained from the national Department of Social Development (DoSD), and an alphabetical list drawn up of all NPOs serving clients affected by HIV and AIDS in the three study provinces. These NPOs were then allotted numbers in sequential order, by province. Pieces of papers with these numbers on them were placed in a container which was shaken and the researcher drew papers from the container, one by one, until seven numbers representing NPOs were identified. The 15 households were then selected systematically, instead of randomly, from the client list of these seven NPOs, to avoid fieldworkers visiting households in close proximity to one another and thus not risk raising community members' suspicions about HIV and AIDS affected households.

The survey sample was recruited in the following way: Potential respondents who were aged 50 years or over and a primary caregiver in a listed, affected household were invited to participate in the study, The aims of the study were explained to them fully and what would be required of them if willing to participate in the study. They were then required to sign an informed consent form (Annexure 1); if unable to read and write, the contents of the form were explained to them fully and they were able to give verbal consent to the fieldworker.

Substitution of households was permitted in cases of refusal and absenteeism. Substituted households were identical to those originally selected: i.e. the house was in the same district or area and an older carer resided in the house. Similarly, NPOs that did not provide support to older carers, such as advice, counseling, food parcels and skills development, were substituted with an NPO that did render these services.

The sampling was thus stratified by province and the sample selection based on a cluster sampling technique (Kish, 1965, 1987; Babbie, 2001). The sampling procedure SURVEYSELECT (SAS V8, 2004) was used, which selects the sample and calculates the sampling probabilities from which the sampling weights are calculated.

4.2.1.3 *The survey instrument*

A semi-structured data collection instrument was specially designed for use in the survey (Annexure 2). The instrument included both fixed-response and open-ended items, and incorporated skip patterns. Thus, while the tool was aimed primarily at capturing quantifiable data, to describe the situations, problems and support needs of older persons who provide care to adult children living with HIV and AIDS and affected grandchildren, it also provided for the capture of narrative responses.

The survey instrument was constructed in two parts: Part 1 provided for the gathering of quantitative data and comprised fixed-response items, in which responses could be measured using nominal scales with dichotomous variables such as yes =1 and no = 2, and ordinal (Likert) scales with ordinal variables such as 1 = excellent, 2 = good, 3 = fair, 4 = poor. This part was divided into six sections: i) A cover page for household and respondent identification purposes: ii) Section 1 for demographic and household data; iii) Section 2 for information on the respondent's health status; iv) Section 3 for assessing the respondent's knowledge and awareness of HIV and AIDS; v) Section 4 on caregiving to persons living with the disease; vi) Section 5 on caregiving to orphaned/grandchildren; and vii) Section 6 on support received from the government and other community structures such as churches.

Part 2 provided for the collection of open-ended (narrative) responses and comprised eight items. Responses to these items provided information on the respondent's own assessment of the most critical needs or challenges in a specific problem area (Burman, 1994). These responses were recorded verbatim. Based on the nature of these responses, the researcher later identified respondents and households for participation in a follow-up, in-depth interviewing study, to produce case studies.

4.2.2 Case study interviews

A case study may be defined by a particular interest in individual cases and not by the method of inquiry used (Stake, in Denzin & Lincoln, 2003). The purpose of gathering data from a "case," or individual, is to understand what is specific and what is different (about that case), and what can be learned about or from the case. In general, case studies are used to gather in-depth and intensive information from individuals whose situations or circumstances may be of particular interest in a study. Case studies can be of an "intrinsic" or "instrumental" nature. In an intrinsic case study, a small group of individuals is studied, while in an instrumental case study, a single case is examined (Welman & Kruger, 2002). An intrinsic case study is directed at understanding the uniqueness and idiosyncrasy of a particular case in all its complexity (Welman & Kruger, 2002). The investigator describes or records what and why the person says, or why he/she behaves in a particular way (Rosnow & Rosenthal, 1996). Such a study can provide a holistic, historical picture of an individual and/or her/his household's situation, such as how the household copes with the impact of HIV and AIDS. In an instrumental case study, a particular case is examined: not for its own sake, but mainly to provide insight into an issue, or to draw a generalisation (Denzin & Lincoln, 2003); the actual "case" is of secondary interest.

Case studies are used in diverse areas, such as in policy making studies, psychology, health research, and any situation that calls for descriptive information such as the depiction of a subject's specific situation (Bromley, 1986). The studies "provide more valid portrayals, better bases for personal understanding of what is going on, and solid grounds for considering action" (Stakes, 1981:32).

In the present study, an intrinsic case study technique was employed. Ten case studies of older carers were conducted in the Western Cape Province only, and not in the other two provinces, for logistical reasons. The ten households were purposively selected (Hammersley, Gomm & Foster, 2000) from the 305 completed questionnaires, and revisited by the researcher within one to three months of the survey interview. The selection of respondents for this study was based on "unexpected" or unanticipated responses given in the survey interviews, which were indicative of their particular situation and of interest to the researcher (Carroll & Johnson, 1990). Examples of "unexpected" responses were beliefs that AIDS could be cured and that HIV is a demon that can only God can remove. Such responses, of a

religious nature, were viewed as unexpected in that the older carers had already been exposed to considerable scientific information and education from the NPO to which they belonged, which seemingly contradicted the knowledge they had about AIDS.

The questions for the case studies, or in-depth interviews, were developed from a preliminary analysis of data recorded in the survey questionnaires. The researcher conducted the interviews himself with the use of a semi-structured interview schedule constructed from these items (Annexure 4).

A case study technique was used to collect the qualitative data, rather than another technique such as focus group discussions. Use of the case study approach was informed by a need to protect respondents from possible embarrassment about their family situation. More importantly, the sensitivity of HIV and AIDS and risk of stigmatisation would mean that the topic would not lend itself to frank discussion. The case study technique allowed the respondents to speak freely in the privacy of their home.

4.2.3 Key informant interviews

Key informants are individuals who are presumed to be knowledgeable about an issue under investigation (Hardon et al., 1995). They may be representatives of institutions or organisations, or people who are accorded special status within a community, such as community leaders, or older people (Kumar, 1986). Advantages of interviewing a key informant are the structured contact that the interview provides and an opportunity to gather detailed information (Doll-Yogerst, n.d.). The technique is particularly useful in the gathering of information to inform policy review and reform (Morton, 2002; USAID, 1996). Other advantages of key informant interviewing are that the information is provided directly by knowledgeable persons; the interviews afford flexibility for the researcher to explore new ideas and issues not anticipated during planning; and the interviews have a low cost. However, a disadvantage of the technique may be bias in the information provided, and to this end the researcher must attempt to ensure that a balance of opinions and views is achieved, through judicious selection of the informants (Kumar, 1986).

Nine key informants, six in government and three at non-profit organisations, were interviewed in the study. One NPO manager was selected in each province with an aim to balance the views, perceptions and opinion of the managers on government policies and

programmes, with those of two senior managers in the departments of Social Development and Health in each province, across the provinces, giving a total of nine key informants. The purpose was to learn about the content and implementation of policies, through strategies and programmes, relevant to the inquiry, and whether the policies are responsive to the needs of older carers – from the informants' perspective, or in their experience or opinion. The semi-structured interviews were guided by a schedule of issues to be discussed (Annexure 5). The researcher framed questions in the interview guide spontaneously, to probe for specific information, and kept notes of responses that were elaborated on later (Kumar, 1986; USAID, 1996).

Interviews were conducted with 1) representatives of government health and social development departments, and 2) NPO managers – in each of the three provinces. The informants were officials presumed knowledgeable about available relevant policies, strategic plans and programmes pertaining to HIV and AIDS and older persons. The key informants selected for interviews is shown in Figure 4.2 below.

Figure 4.2: Profile of the key informants interviewed

	Department/Organisation	Portfolio/Area of activity	Designation
	Government informants		
1	Department of health (EC province)	HIV/AIDS directorate	Director
2	Department of Social Development (EC province)	Social Services directorate	Director
3	Department of health (KZN province)	HIV/AIDS directorate	Manager
4	Department of health (WC province)	HIV/AIDS directorate	Manager
5	Department of Social Development (WC province)	Social Services directorate	Manager
6	Department of Social Development (KZN province)	Social Services directorate	Manager/Director
	NPO informants		
7	Jersey Farm Older Person Support (EC)	HIV/AIDS support	Manager
8	Nobuhle Community Project (KZN province)	HIV/AIDS support and home based care	Manager/Co-ordinator
9	Grandmothers Against Poverty and AIDS (WC province)	HIV/AIDS support and income generation	Director/Co-ordinator

4. 3 DATA COLLECTION

4.3.1 Survey data collection

All items in the survey instrument were deemed relevant to an understanding of the nature, extent and problems of caregiving relating to HIV and AIDS. The instrument was developed by the researcher in English, and translated into the relevant languages of the study population by first-language speakers, all of whom had a tertiary qualification in a specific language. The instruments were then back translated into English by a researcher not associated with the study. The instrument was administered in face-to-face interviews conducted in the respondents' homes – as far as possible in a private place. The three master's students used were versed in the three African languages namely isiZulu, isiXhosa and Afrikaans. They were also fluent in English. They were also contracted to validate the translation of the questionnaire through back translation and standardisation to remove ambiguities.

The questionnaires were administered in a respondent's preferred language. The duration of the interviews was estimated to be less than 60 minutes. Entry to the households was facilitated by the NPO or CBO from whose client list a household was selected. Specially trained fieldworkers (see Section 4.3.1.1 below) were accompanied to the house by a home-based carer engaged by the NPO (but who was not present during the interview). The fieldworkers were deployed to areas where they were not known. After each interview, a fieldworker leaved behind a pamphlet with the respondent that had a list of relevant resources in the area from which the respondent could seek assistance, if he/she so wished (Annexure 3).

If no participant (an older carer) was found at a household visited by the fieldworker on three visits at different times on the same day (morning; midday and late afternoon), a "non-response" was recorded on the questionnaire. Such households were thereupon substituted with another household that met the study selection criteria.

4.3.1.1 *Recruitment and training of fieldworkers*

Twelve fieldworkers were recruited and trained to gather data for the study: four in each province. All had at least a Grade 12 level of education (they had matriculated). They had

special training on i) knowledge about HIV and AIDS; ii) a brief history and the current state of the epidemic in South Africa; and iii) sexually transmitted infections (STIs) and other modes of transmission of the HI virus. The fieldworkers were trained in developing rapport with respondents; how to interview an older person (e.g. speak slowly, clearly and loud enough); reading the consent form to the respondents; administering the questionnaires; and on the ethics of the study, especially relating to the sensitive issue of HIV and AIDS and associated stigma. Role play was used to model real interview situations; the fieldworkers took turns to interview one another during training, observed and redirected by the researcher. A risk of fieldworkers misinterpreting the meaning of an item was minimised through the role play; they were guided in reaching a common understanding of what an item sought to elicit or measure. The fieldworkers all belonged to the same ethnic group as the respondents in the different provinces.

All interviewers were trained extensively in interviewing and the interview process. "Real" interview settings were simulated in which the interviewers carried out role play by interviewing one another. Information gathered from the mock interviews was checked for completeness before the start of the field work; the data from these interviews were then discarded and not included therefore with the survey data.

Supervisors were trained in monitoring the field work and checking completed questionnaires when returned from the field. Where information was missing, interviewers were sent back to a respondent to collect the data.

4.3.1.2 *Field set-up logistics*

Prior to conducting the fieldwork, telephonic and face-to-face consultation was carried out by the researcher with the manager or co-ordinator of an NPO/CBO/FBO. An appointment was made with the relevant person at the organisation for a meeting, during which the researcher explained the nature and purpose of the study fully.

4.3.1.3 *Pre-testing of the survey questionnaire*

The survey instrument (Annexure 2) was pre-tested on five older persons who resided in the researcher's neighbourhood, to test the wording and clarity of the items (to eliminate unclear or ambiguous phrasing) and their logical sequence in the instrument. The instrument was subsequently refined accordingly.

4.3.1.4 *Piloting of the survey questionnaire*

A pilot study was conducted by the researcher on a 5 per cent sample (n =10 households) using the survey instrument (Annexure 2). Minor adjustments were made to the instrument after completion of the pilot study. The informed consent form was "tested" in the pilot study as well and found to be satisfactory. The duration of interviews ranged between 30 and 45 minutes. The pilot study questionnaires were not included in the survey sample. Problems of readability and flow of the questionnaire were checked during the pilot study.

4.3.1.5 *Problems encountered during fieldwork*

Minor problems were encountered during the fieldwork, which were dealt with in the following ways: As the study inquired about older carers' support needs, and what respondents' perceptions were of what the government should provide for them, the interviews ran the risk of creating expectations in the respondents that could not be met by the study in the short term. This risk was addressed in the information/consent form, where the purpose of the study and expected outcomes were outlined. Where it became apparent that expectations had been raised in a respondent, the fieldworkers were instructed to refer the respondent to the signed informed consent form. The fieldworkers were also trained to manage situations such as emotional outbursts. However, no untoward problems were reported regarding any of the above.

Some difficulty was experienced though in certain fieldworkers not starting fieldwork on some days on time, and some fieldworkers lost study materials which needed to be replaced. Some fieldworkers reported a shortage of money for transport. Finally, inclement weather in some settings delayed the progress of fieldwork. The latter problems were however of a logistical nature and were managed satisfactorily by the researcher.

Where fieldworkers experienced operational problem(s) in the field, the following procedures were followed:

4.3.1.6 *Recording of responses*

In general, all responses and their corresponding codes were recorded on the questionnaire (Annexure 2) by marking an X, except where a question had to be skipped according to skip pattern instructions. A "no response" option was deliberately excluded to discourage interviewers from taking an easy response option.

4.3.1.7 *Pre-coded questions*

Most questionnaire items were pre-coded and only one response was provided for each item. In some items an "Other" option was provided. In these cases, the interviewer was required to write out the respondent's full response, verbatim as far as possible. The formatting of items is shown in the questionnaire in Annexure 2.

4.3.2 Case study data collection

The interview schedule employed to gather information from selected respondents in the unstructured, in-depth interviews, towards compiling the case studies, comprised open ended questions (Annexure 4). The instrument was administered by the researcher, who recorded the responses, or narratives manually, as far as possible verbatim, on the schedule. Where a respondent gave consent, an interview was audio-recorded.

4.3.3 Data collection during interviews with the key informants

Data were collected from the key informants by the researcher using the specially constructed interview schedules: Annexure 5 in the case of government informants and Annexure 6 in the case of the NPO informants. All interviews were conducted in English. The informants' responses to the set of topics for discussion were recorded on the schedules, as far as possible verbatim. Of the nine interviews, five were audio-recorded with the informants' consent. In general, the informants were co-operative and discussion flowed freely. However, some explained that they had only been appointed to their position recently, and were not as knowledgeable about the topic of discussion as they would like to be, but were nevertheless willing to assist as far as they could. The data collected primarily related to the informants' views on and understanding of the government's management of HIV and AIDS, and policy intervention, or lack thereof, as it related to older carers' support needs.

4.4. SEQUENCE OF THE DATA COLLECTION

The collection of qualitative data followed on the completion of the survey and preliminary analysis of the data. The survey data highlighted the nature and magnitude of problems older carers experienced, and this information helped the researcher to develop items to guide data collection in the qualitative follow-up study. Qualitative data were not collected prior to the survey for the following reasons: i) Knowledge in the subject area is fairly expansive and

additional exploration at that stage was considered not warranted. Pre-survey exploration would indeed have been carried out if little was known in the area of investigation, as argued by Creswell (2003). ii) First-hand interaction of the researcher with older carers while employed as a researcher at the Human Sciences Research Council had equipped him with an understanding of older carers' burden. iii) The identification of topics for follow-up in the qualitative in-depth study was based on an analysis of the survey data, and collection of qualitative data after completion of the survey is thus self-explanatory.

4.5 DATA MANAGEMENT

4.5.1 Collation of the completed questionnaires

One of the four fieldworkers in each province was designated as a supervisor, and was responsible for the collection and enumeration of all completed questionnaires. The three supervisors checked the questionnaires on the day they were administered, to ensure identification and rectification of errors in the field immediately. Each checked questionnaire was reviewed with the responsible fieldworker. If a supervisor was not satisfied with a completed questionnaire, the fieldworker was required to revisit the respondent and correct the errors.

All the questionnaires were checked additionally by the supervisors to ensure that i) all skip and filter instructions had been followed; ii) all responses were legible; iii) only one response code for an item had been crossed (X) – unless instructions permitted more than one response; and iv) responses to the open-ended items had been recorded satisfactorily.

At various stages, the supervisors placed all completed questionnaires in an envelope, sealed it, and recorded the number of completed questionnaires and consent forms for that district and the date of completion in a record book. The questionnaires were couriered to the Human Sciences Research Council's office in Cape Town on a weekly basis.

4.5.2 Data capture

4.5.2.1 *Quantitative data capture*

The survey data were captured by trained data capturers at the Human Sciences Research Council in Cape Town using SPSS version 15.0. The accuracy and completeness of the questionnaires, especially where open-ended items were concerned, were checked again for corresponding responses to the items and that skip patterns had been followed correctly. Frequency distributions were run to check that all variables contained values in the accepted range and variable labels or definitions. Outlying values were followed up and corrected.

4.5.2.2 *Qualitative data capture*

The data collected in the two qualitative studies were captured as follows: On completion of an interview with a respondent in the follow-up, in-depth interviewing study, the researcher wrote up raw field notes and later transcribed them into a word processor. The raw (verbatim) data were similarly captured in a word processor, and translated from Xhosa to English by the researcher; transcripts of the translations were later verified by an independent translator (a person with tertiary education degree). Summary notes of the captured data were made in preparation for content analysis and interpretation.

At the end of an interview with a key informant, the researcher wrote a summary, in which themes and issues in the information provided by the key informants were recorded. Insights developed by the researcher during an interview were linked to the information. Audio-recorded data were transcribed by the researcher and categorised in domains**.** Where interviews were not audio-recorded, the researcher wrote up the manually recorded information and managed it similarly.

4.6 DATA ANALYSIS

Data analysis was undertaken in three parts: 1) The survey data; 2) the qualitative case study data; and 3) and the key informant interview data.

4.6.1 Survey data analysis

Analysis of the quantitative data was descriptive: characteristics of the sample were described (Hardon et al., 1995; Katzenellenbogen, et al., 1991) using the SPSS programme as follows:

4.6.1.1 *Univariate analysis*

Frequency distribution tables, graphs and measures of central tendency such as means, standard deviation and score ranges were compiled. Cross tabulations were made, e.g. between caregiving and receipt of support – such as a government grant, and between caregiving and marital status. Age means were compared using analysis of variance (ANOVA), while cross tabulations and categorical variables were analysed applying the chi squared technique. Fisher Exact test was employed whenever any cell was less than 5. All analyses were carried out using SPSS version 17.0. A probability value of 0.05 or less was taken as significant.

4.6.2 Case study data analysis

The captured data were classified and content analysed. Content analysis was used to determine the presence of certain words or concepts within texts or sets of texts. The text was broken down into manageable categories on a variety of levels – e.g. words, phrases, sentences or themes – and then examined using a basic method of content analysis, e.g. conceptual analysis (Krippendorf, 2004). The purpose of classifying qualitative data for content analysis is to facilitate the search for patterns and themes within a particular or across cases (Patton, 1990). First, comprehensive information is gathered on each case: i.e. interview data, observation data, and researcher impressions about the case. Once accumulated, a case record is written up, which involves pulling together and organising all of the data about the case. After this, the organised information is edited, redundancies are removed, and information that belongs together is combined in categories. The case record is then arranged topically for easy access. Thus, case records represent data organised at a level beyond raw case data.

Analytical categories in which the data were organised in the unstructured interviewing study were: i) A socio-demographic profile of the caregivers; ii) a description of their health status; iii) their level of knowledge of HIV and AIDS; iv) formal and informal support available to them; v) the household members' knowledge of the status of the PLWHA and related stigma; and vi) the carers' concerns about co-resident grandchildren and him/herself.

Additional analysis entailed comparing and contrasting cases. Nonetheless, each case was understood as a representation of a particular phenomenon of interest to the study.

4.6.3 Key informant interview data analysis

The data from the key informant interviews was content analysed in a similar way to the data for the case studies. The key informant interview data was organised in six domains: 1) Knowledge of and availability of policies and programmes to support older caregivers; 2) the role of the provincial government department or NPO in providing support to caregivers; 3) older persons,' or their representative bodies' participation in policy formulation processes; 4) their participation in the monitoring and evaluation of implementation of policy recommendations; 5) the availability of resources to facilitate older caregivers' participation in the development and implementation of HIV and AIDS policies and/or strategic plans; and 6) the informants' opinions on how national policy makers can enable district managers to coordinate activities at a local level in order to support older person households affected by HIV and AIDS.

4.7 TRIANGULATION OF THE DATA

When data have been collected from multiple sources, using a combination of research approaches and techniques – hence, a mixed-methods approach, the data (and results of analyses of the data) need to be triangulated (Green, Caracelli, & Graham, 1989; Silverman, 1993; Morgan, 1998; Creswell, 2003). Triangulation will achieve an integrated and comprehensive analytical outcome and understanding. Thus, triangulation represents synergy in the use of quantitative and qualitative methods, which, when used together, yield "more than the sum of the two approaches used independently" (White, 2002: 513).

In the present study the data from the quantitative and qualitative studies would be gathered sequentially: collection and analysis of the quantitative (survey) data would be followed by the collection and analysis of the qualitative (unstructured interview) data. Although an initial focus would be on the quantitative data, the data of the two qualitative studies would then need to be integrated with the survey data. Thus, results of the analysis of the qualitative data (the analyses of the data from the multiple sources shown in Chapter 5) would be used in an interpretation of the findings of an analysis of the quantitative data. When triangulated, should unexpected results arise in the analysis of the quantitative data – as suggested by Morse (1991), the results of the analyses of qualitative data could be used to examine the surprising, or unexpected results in more detail.

At the same time, understanding the support needs of caregivers at a household level through an analysis of the qualitative data will be useful, if policy recommendations are to be made to address those needs. Such an understanding would not be achieved from an analysis of data collected using a structured survey questionnaire alone. The results of the analyses of the data from the multiple sources, in terms of the use of a mix-methods design, should thus be triangulated, towards the end of the analyses of the data in Chapter 5. Statistical techniques will not be employed in the triangulation of the data; rather, the three sets of data will be integrated (triangulated) qualitatively and comparatively, largely to identify areas of convergence and/or divergence (Creswell, 1994).

4.8 LIMITATIONS OF THE STUDY METHODOLOGY

All research methodology and research designs have limitations, and the present study has its own biases and limitations. How bias may have entered the study and the data, and how the bias was managed, as well as other limitations of the study are discussed below.

- All households visited appeared on a list of clients of NPOs included in a database compiled by the relevant provincial departments of Health and Social Development. The survey sample was thus biased towards households with a co-resident older carer that had access to some form of intermediate support from an NPO, through the government's subsidisation of the NPO, and appeared on that list of NPOs. The results cannot thus represent the general population of households with PLWHA, that may not benefit through assistance from NPOs or other support agencies, that receive government subsidisation. Moreover, a large number of affected households in which an older carer is resident, which do not access support from a subsidised NPO, may not be represented in the dataset;
- The survey sample was drawn in only three of South Africa's nine provinces. Affected households' situations and caregiving practices and challenges in the other six provinces may differ. The study findings will thus not be generalisable to affected households in the other provinces, or to South Africa as a whole;
- The study findings may neither be generalisable to households that differ demographically from those in the departments' database: e.g. households without co-resident grandchildren and households in the other six provinces.

- Carrying out case studies in only a single province is similarly a limitation of the qualitative component of the study data.
- The inclusion of only three NPO key informants also limits generalisation of the key informant data.
- Bias may appear in the case study data through the purposive selection of the respondents for these studies, as well as the selection of the key informants;
- The problem of stigma associated with HIV and AIDS prevented the identification and random selection of households, through sensitivities in approaching the households, or indeed the households' access of help from an NPO. Thus not all affected households with an older carer had an equal probability of being recruited into the sample;
- Some bias may have occurred due to the non-response, or refusal of some respondents to be interviewed, whose responses may have differed (e.g. socio-economically) from those who agreed to participate in the study, as well as in the non-solicitation of information on household income and expenditure.
- Although careful measures were taken to reduce bias, bias may nevertheless entered the qualitative data during the translation of the transcripts from the language in which an interview was conducted into English;
- The non-inclusion of a control group of older persons who do not care for PLWHA in their household may limit generalisation of the findings to the population of older caregivers;
- The non-application of standardised instruments to measure caregiver stress, depression, anxiety and burden of care, because of a lack of such an instrument validated in an African setting, may be an omission, but was occasioned by a methodological dilemma and decision.

Limitations of the study methodology as a result of factors extraneous to the study's objectives are as follows: 1) The study did not discern between older carers who care for a PLWHA on anti-retroviral treatment and a PLWHA not on treatment, or a PLWHA who is using alternative treatments such as herbs from a traditional healer, or a combination of therapies. 2) The dissertation makes only a limited contribution to an understanding of the extent that cultural norms played a role in the empirical study's overwhelmingly female caregiver profile. 3) The study was unable to differentiate the extent, or impact of the

caregiving burden on older carers who are beneficiaries of an old age grant and those who do not receive a grant – in the latter case possibly owing to age ineligibility.

4.9 ETHICAL CONSIDERATIONS

Ethical considerations of the study and how they were dealt with are outlined below:

- Ethical approval to conduct the study was obtained from the Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (Application Number REC 335/2005) (Annexure 7);
- An information/consent form (written in the language of the respondent) explaining the purpose of the study and how the data would be managed was handed to each respondent who indicated a willingness to participate in the study. A respondent was assured that he/she could withdraw from the study at any time and without any penalty to him-/herself. On recruitment, a respondent was required to sign an informed consent form (Annexure 1), written in his/her own language, which was explained fully to the respondent by the fieldworker. Signature of the form indicated his/her understanding of what would be required of him/her, and that he/she was not coerced but willing to participate in the study;
- Neither a respondent's name nor address appeared on the cover sheet of a questionnaire submitted for data capture. The anonymity of all respondents in the reporting of the study results was thus ensured, and was adhered to during data capture and analysis of the data;
- No invasive procedures or tests were carried out on the respondents;
- A pamphlet with local useful resource information (e.g. offices that provided information and advice on HIV and AIDS, financial assistance, social work services, volunteering services and office counselling) (Annexure 3) was handed to each participating household at the end of the interview;
- Information provided by the survey respondents, the sub-sample for the case studies and the key informants was kept confidential by the researcher. No key informants are identified in the capture and analysis of the data. The completed questionnaires and interview schedules, and the audio-recordings will be destroyed once this thesis has been accepted;

- No remuneration or incentive, in cash or kind, was given to the respondents, to avoid a risk of bias in the recruitment of the sample and the data, and to minimise a risk of violation or exploitation of fieldworkers in the field. Participants were informed that the information they provided would assist policy makers and the planners of support programmes for older caregivers such as themselves (see Annexure 1), but that participation in the study would not offer them any direct material benefit.

CHAPTER FIVE: ANALYSES OF THE DATA

5.1 INTRODUCTION

Data collected in the survey in the three provinces were captured and analysed using the SPSS programme. Data collected in the follow-up, in-depth interviews with ten of the original survey respondents were content analysed and written up as case studies (the case studies are shown in Annexure 1). Data collected in the semi-structured interviews with nine key informants – six government representatives and three managers of NPOs that serve older persons – were similarly managed and content analysed. In the case of both qualitative studies – that is, the latter two studies – the interviews were audio-recorded where the respondents and informants consented to audio-recording. In three cases, key informants did not consent and their responses to open questions were recorded manually by the researcher. Transcripts of audio-recordings and manual records, translated from Xhosa into English, were content analysed by the researcher.

The results of the analyses of the data from the three sources – a quantitative survey and two qualitative studies – are presented in three parts: Part 1: Analysis of the survey data; Part 2: Analysis of the in-depth interview data; and Part 3: Analysis of the data from the key informant interviews. The study data were therefore collected using a mix of quantitative and qualitative research methods. The results of the analyses of the three datasets are triangulated towards the end of the chapter.

PART 1: SURVEY DATA

5.2 ANALYSIS OF THE SURVEY DATA

5.2.1 Realised sample

The realised sample for the survey is shown in Table 5.1 below. During sampling a concerted effort was made to ensure a high recruitment rate. To this end, i) meetings were held with the management of sampled NPOs (who directed interviewers to affected households with older carers) to explain the aims and purpose of the study, and to elicit the NPO's assistance; ii) only interviewers who had matriculated and were involved in a campaign to combat HIV and AIDS at a community level (e.g. as HIV counsellors) were recruited to conduct interviews;

and iii) up to three revisits to a household to recruit a respondent (if the respondent was absent on previous

Table 5.1: Realised survey sample, by province, geographical area and gender (percentage distribution and frequencies)*

Province	Gender				Total	
	Males		Females			
	%	n	%	n	%	N
KwaZulu-Natal						
Urban[1]	8.3	6	91.7	66	-	72
Non-urban[2]	-	-	100.0	30	-	30
Subtotal	22.2	6	34.5	96	33.4	102
Eastern Cape						
Urban[3]	25.8	8	72.4	23	-	31
Non-urban[4]	13.8	9	86.2	56	-	65
Subtotal	62.9	17	28.4	79	31.5	96
Western Cape						
Urban[5]	1.4	1	98.6	68	-	69
Non-urban[6]	7.9	3	92.1	35	-	38
Subtotal	14.8	4	37.1	103	35.1	107
Total	8.8	27	91.1	278	100.0	305

* Percentages in columns in this table and subsequent tables may not have added up to 100 and have been rounded off.

1 Chesterville, Umlazi and Lamontville (Durban).
2 Edendale, Pata, Ntuzuma, Swayimane and Mbalenhle (Pietermaritzburg).
3 Umtata and Newrest.
4 Lusikisiki and Flagstaff.
5 Khayelitsha, Nyanga and Gugulethu (Cape Town).
6 Ashton, Robertson and Maccassar.

visits) were undertaken before the household was substituted with another household in the same geographical area.

Three NPOs, which the researcher approached initially for referrals to households that would meet the study criteria, refused to participate in the study: one in the Western Cape Province and two in the Eastern Cape Province. These NPOs were substituted with NPOs that operated in the same geographical area and did similar work. The main reasons advanced by the three NPOs that refused to participate were a need to protect the identity of their clients, and that

neither the NPO nor clients had ever been given feedback by researchers whom they had helped previously. Numerous NPOs and respondents in the course of the survey in fact complained that they did not benefit directly from research in which they participated. Two NPOs in the Eastern Cape Province, operated by older persons and aimed at supporting orphaned children, did not support older carers of PLWHA as such, and did not therefore meet the criteria for inclusion in the survey sample.

Despite the refusal of three NPOs and six households to participate in the survey, a 100 per cent response rate was achieved through substitution. The sample substitution rate for NPOs was 14.3 per cent and for households, 1.9 per cent. The total sample numbered 305 older carers.

Table 5.1 gives a breakdown of the realised sample by province, geographical area and gender, shown as percentage distributions and frequencies. The largest provincial sub-sample realised was in the Western Cape (WC), followed by the sub-samples in KwaZulu-Natal (KZN) and the Eastern Cape (EC).

5.2.2 Socio-demographic profile of the sample

The socio-demographic profile of the survey sample is shown in Table 5.2, according to province and geographical area, as percentage distributions. More than nine in ten (91.1%) respondents who were primary carers to PLWHA and OVC were female. The majority of the respondents were of South African descent. The mean age of the sample was 65.9 years (SD = 8.3 years). The mean ages by province were Eastern Cape: 65.5 (SD = 7.4) years; Western Cape: 63.5 (SD = 8.7); and KwaZulu-Natal: 68.7 (SD = 7.8) years. The differences were not significant ($F = 1.42$, $p = 0.06$.) The mean age of the male respondents was 63.4 years and of female respondents, 66.1 years.

More than four-fifths of the sample (86.2%) headed their household, i.e. they were the main decision maker in the household. Most spoke one of two major Nguni languages in South Africa, namely isiXhosa and isiZulu. Three-quarters of the sample (75.6 %) was aged 60 years and over. Only slightly more than a third (35.5%) was still married; thus almost two-thirds (64.5%) may have lacked the support of a spouse and been vulnerable. Only three in ten respondents (29.5 %) had had an education level beyond Standard 6 (eight years of

schooling). In general, respondents in urban areas in all three provinces reported a higher education level than their rural counterparts.

Table 5.2: Socio-demographic profile of the survey respondents, by three provinces and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Total	100	100	100	100	100	100	100
N	31	65	72	30	69	38	305
Nationality							
South African	100.0	96.9	93.1	100.0	100.0	100.0	97.7
Other	-	3.1	6.9	-	-	-	2.3
Head of Household							
("yes" responses)	77.4	87.7	86.1	100.0	82.6	86.8	86.2
Home language							
isiXhosa	96.8	98.5	11.1	6.7	98.6	73.7	65.6
IsiZulu	3.2	1.5	88.9	93.3	-	-	30.8
Sotho	-	-	-	-	1.4	-	0.3
Afrikaans	-	-	-	-	-	26.3	3.3
Age group (years)							
50-54	3.2	7.7	2.8	-	10.1	18.9	7.2
55-59	25.8	13.8	8.3	6.7	31.9	13.5	17.1
60-64	29.0	24.6	20.8	23.3	15.2	16.2	21.0
65-69	25.8	24.6	27.8	40.0	21.7	32.4	27.3
70+	16.1	29.2	40.3	30.0	20.3	18.9	27.3
Marital status							
Married	19.4	23.4	44.4	66.7	30.4	36.8	35.5
Widowed	41.9	59.4	20.8	20.0	27.5	42.1	35.2
Separated	9.7	4.7	6.9	-	8.7	13.2	7.2
Never married	25.8	9.4	19.4	13.3	27.5	7.9	17.8
Divorced	-	1.6	5.6	-	5.8	-	2.9
Living together	3.2	1.6	2.8	-	-	-	1.3

Cont/.

Table 5.2 continued:

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Highest level of education							
No schooling	16.1	13.8	13.9	40.0	2.9	15.8	14.4
Sub A and Sub B	6.5	7.7	22.2	13.3	4.3	7.9	10.8
Standards 1 to 3	16.1	26.2	23.6	26.7	14.5	15.8	20.6
Standards 4 to 6	35.5	26.2	25.0	16.7	39.1	31.6	29.5
Standards 7 to 9	19.4	18.5	8.3	3.3	24.6	23.7	16.7
Matriculation	-	4.6	1.4	-	5.8	2.6	3.6
Post matriculation	6.5	3.1	5.6	-	5.8	2.6	4.3

In summary, the predominantly female sample had a low level of education – and by implication, few opportunities for self-advancement and poor access to resources across the life course. The majority of the sample was 60 years or older, and the majority lacked a spouse and therefore spousal support. The majority of the respondents, all of whom were burdened with caregiving, may thus have had heightened vulnerability.

5.2.3 Household information and characteristics

The characteristics of the respondents' households indicate the social and economic situation of the caregivers. Table 5.3 shows that the majority (68.9%) had lived in the same residential area for more than ten years, although more non-urban than urban caregivers had done so. Close to two-thirds of the sample had lived in the same dwelling for more than ten years, with more non-urban than urban respondents having done so, with the exception of respondents in the Western Cape Province.

Table 5.3: Characteristics of the respondents' households, by three provinces and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Duration of respondent's stay in area							
< 1 year	-	1.5	1.4	6.7	-	-	1.3
1- 2 years	6.5	4.6	6.9	3.3	-	-	3.6
3- 5 years	29.0	6.2	12.5	-	2.9	13.2	10.0
6- 10 years	32.3	15.4	26.4	3.3	7.2	15.8	16.1
> 10 years	32.3	72.3	52.8	86.7	89.9	71.1	68.9
Duration of respondent's stay in dwelling							
< 1 year	3.2	1.5	8.3	0.0	1.4	5.3	3.6
1-2 years	6.5	6.2	13.9	6.7	-	-	5.9
3-5 years	32.3	7.7	9.7	10.0	5.8	15.6	11.5
6-10 years	29.0	10.8	22.2	10.0	8.7	15.8	15.4
> 10 years	29.0	73.8	45.8	73.3	84.1	63.2	63.6
Household's sources of water (multiple responses permitted)							
River/water stream/pond	59.4	70.0	-	10.3	-	3.2	21.8
Tap (inside house)	16.7	7.8	38.6	3.6	58.8	52.6	32.9
Tap (in the yard)	54.8	23.4	37.1	40.0	31.1	23.7	33.3
Communal tap	38.9	61.1	68.2	31.2	39.3	43.5	41.2
Household's type of toilet facility							
Flush toilet inside house	12.9	7.7	37.5	-	36.2	44.7	25.6
Flush toilet in yard	6.5	6.2	13.9	-	43.5	21.1	17.7
Public flush toilet	-	3.1	-	-	7.2	-	2.3
Pit latrine	71.0	70.8	48.6	100.0	-	31.6	47.5
Bucket toilet	-	1.5	-	-	13.0	-	3.3
Chemical toilet	9.7	3.1	-	-	-	2.6	1.9
No toilet (uses bush, etc.)	-	7.7	-	-	-	-	1.6

Cont/.

Table 5.3 continued

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Household's sources of energy (multiple responses permitted)							
Timber/wood	80.0	56.2	9.7	40.0	1.6	10.5	28.5
Electricity	71.0	73.4	94.4	73.3	84.1	81.6	81.6
Coal/anthracite	6.7	3.2	-	3.3	1.6	-	2.0
Paraffin	62.5	76.7	23.6	3.3	36.1	26.3	38.3
Gas	6.8	8.1	9.9	3.4	6.8	8.1	8.6
Size of dwelling							
One room	6.5	4.6	9.7	10.0	5.8	2.6	6.5
Two rooms	19.4	18.5	34.7	6.7	14.5	18.4	20.3
Three rooms	54.8	35.4	11.1	23.3	20.3	34.2	26.9
> Three rooms	19.4	41.5	44.4	60.0	59.4	44.7	46.2
Household's sources of income (multiple responses permitted)							
Social old age pension	79.2	20.8	59.4	40.6	43.7	57.0	65.9
Child support grant	20.9	49.2	33.3	26.7	50.7	68.4	43.9
Employer pension	9.7	10.8	8.5	3.3	-	2.6	5.9
Remittance from family	20.0	6.2	13.9	-	-	5.3	7.2
Employment	3.2	6.2	7.0	-	13.0	13.5	7.9
Self-employed	19.4	3.1	13.9	-	13.0	10.5	10.2
Hawking/odd jobs	9.7	6.2	2.8	3.3	15.9	2.6	7.2
Welfare organisation	3.2	3.1	8.3	-	1.4	-	3.2
No income	3.2	1.6	8.5	7.7	4.4	6.1	5.0
Household's perceived financial situation ("yes" responses)							
Not enough money for basic expenses	38.9	61.1	62.0	38.1	64.4	35.6	78.0
Have enough money for food/clothes, not other things	16.7	83.3	86.2	13.8	85.7	14.3	33.6
Have most basic household items	34.7	65.3	75.7	24.3	81.7	18.3	47.9
Have some money for extra things	-	100	-	-	20.0	80.0	2.9

Table 5.3 reflects the extent to which a large number of the households lacked basic amenities. Slightly over two-fifths (41.2 %) obtained water from a communal tap; only a third (33.3 %) had piped water inside the dwelling; and the remainder (21.8 %) were dependent on water from unprotected sources such as a river, stream or pond. Households in the Eastern Cape Province were more dependent on an unsafe water source (urban households 59.4 %, non-urban households 70.0 %) than households in the other provinces. Households with no inside piped water lacked an inside flush toilet – a particular hardship for both older carers and PLWHA. Almost half of the households (47.5 %) used a pit latrine: more than two-thirds of caregivers in urban and non-urban areas of the Eastern Cape and all caregivers in the non-urban area of KwaZulu-Natal did so.

More than three quarters (81.6 %) of the households had electricity and more than a third (38.3 %) used paraffin as the main source of energy. More than two in five caregivers (46.2 %) lived in a dwelling with three or more rooms; fewer than a third (26.9 %) lived in three-roomed dwellings. In non-urban areas, the respondents' dwellings were mainly built from inexpensive materials such as mud bricks and thatched roofs. In urban areas, the dwellings were either built with brick, or in the case of shacks, with timber and galvanized corrugated iron.

As is evident in Table 5.3, most of the caregivers' households in this study were of low socio-economic status. The majority of the caregivers and household members also depended on state social security. Two-thirds (65.9 %) of the respondents received a social old age pension; a quarter (24.3 %) were not yet age eligible to receive one. More than two fifths (43.9 %) of the households received one or more child support grants. Only a small percentage of caregivers (10.2 %) reported that they generated income by selling perishables in their communities to supplement their household's income. Reporting on the household's financial situation according to fixed statements, more than three-quarters of the caregivers (78 %) perceived that their household did not have enough money, and less than half (47.7 %) reported that their household had money for basic items. Across all households, the social old age pension appeared to be the household's main source of income. However, a quarter of the caregivers did not access the grant, because they were not yet age eligible to do so.

5.2.4 Health status of the respondents

Two measures were used to assess the health status of the sample: 1) A self-rated health status scale which indicated the respondents' rating of their health as "excellent, "good," "fair" or "poor." 2). A comparative health status scale which required the respondents to rate their health as "better," "the same" or "worse" than that of their peers**.** Table 5.4 shows that four-fifths of the respondents overall (81.3 %) rated their health as fair to poor, while almost three in ten (28.2 %) and three in five (60 %) in KwaZulu-Natal's non-urban areas rated their health as poor, respectively. When asked to compare their present health status to that of their peers, slightly more than three-quarters (76 %) rated their health as the same or worse than that of their peers.

The respondents reported having a number of chronic conditions that may have compromised their health and functioning. A list of self-reported conditions, and indication of whether a condition was being treated or not, are shown in Table 5.5. Leading chronic health conditions in the sample were hypertension (60 %), arthritis (55.3 %) and stress (42.9 %).

5.2.5. Respondents' knowledge of HIV and AIDS

The percentages of caregivers who reported they were knowledgeable about HIV and AIDS (84.3 %), shown in Table 5.6, was high. Although almost all (97.3 %) knew that AIDS is caused by a virus, more than half of the caregivers in non-urban areas of the Western Cape Province believed that AIDS is punishment from God.

Slightly more than two-thirds of the caregivers had learnt about HIV and AIDS from health professionals (67.6 %), followed by the radio (61.3 %) and television (50.9 %) as main sources of information. More than four in five respondents (83 %) reported that they had understood the information provided. Slightly more than nine-tenths (94 %) knew that HIV can be transmitted through unprotected sex. Four in five (80.3 %) knew that the virus can be contracted through an exchange of body fluids, such as blood. Overall, the caregivers' knowledge of modes of transmission of the virus was therefore high.

Table 5.4: Health profile of the respondents, by province and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Self-rated health Status							
Excellent	-	3.1	4.2	-	5.8	5.3	3.6
Good	29.0	15.4	18.1	-	7.2	23.7	15.1
Fair	61.3	70.8	44.4	40.0	46.4	55.3	53.1
Poor	9.7	10.8	33.3	60.0	40.6	15.8	28.2
Self-rated health Status compared to peers							
Better	19.4	32.3	15.3	6.7	36.2	21.1	23.9
Same	64.5	50.8	34.7	26.7	21.7	63.2	40.9
Worse	16.1	16.9	50.0	66.7	42.0	15.8	35.1

5.2.6. Informal help received by carers with daily caregiving to PLWHA

Types of informal help that the caregivers reported they received from various persons or agencies are shown in Table 5.7. When the carers were asked whether they receive any informal support with daily caregiving, less than two-thirds (59.3 %), on average, replied that they do receive support.

Table 5.5: Self-reported health conditions of the sample, and whether the conditions are treated of untreated, by sub-sample and geographical area (percentage distribution)

Condition	Geographical area sub-samples				Total
	Urban		Non-urban		
	Yes, treated %	Yes, untreated %	Yes, treated %	Yes, untreated %	
Health-condition (multiple responses permitted) [1]					
Hypertension (n= 305)	51.7	7.0	51.9	9.8	60.0
Arthritis (n =305)	44.4	14.6	35.3	15.0	55.3
Stress (n = 303)	15.3	37.1	9.0	21.8	42.9
Vision problem (n =301)	19.0	8.5	14.3	18.5	37.5
Loss of memory (n= 303)	10.0	34.7	6.0	18.8	36.0
Diabetes (n=297)	27.1	6.6	19.8	5.3	30.0
Depression (n=299)	13.6	16.6	3.8	5.4	21.0
Hearing problem(n=303)	5.9	11.8	1.5	12.8	16.2
Asthma (n=304)	8.1	2.9	9.1	0.0	10.2
Kidney condition(n=297)	3.6	4.8	6.1	5.3	9.7
Heart condition (n=305)	6.5	2.4	5.3	4.5	9.2
Shortness of breath(n=299)	5.4	6.0	2.3	3.0	8.7
Stomach ulcer (n=304)	4.7	5.3	3.8	1.5	7.8
Tuberculosis (n=304)	1.6	1.3	3.6	-	6.5
Stroke (n=305)	1.8	1.8	0.8	-	2.3
Epilepsy (n=305)	1.2	1.8	0.8	0.8	2.2
Cancer (n=305)	1.2	0.6	1.5	-	1.6

Missing values ranged from one to 12 and were for the following variables: marital status; main source of income; health status; caring for OVC; and organisational affiliation. The missing data may be accounted for by refusal to answer sensitive questions such as marital status, a respondent being uncertain of how to respond. Of the 64 variables measured, data for six variables were missing owing to the foregoing reasons.

Table 5.6: Respondents' knowledge and beliefs about HIV and AIDS, and sources of knowledge, by province and geographical area (percentages of "yes" responses)

Knowledge/belief	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Perceived knowledgeable about AIDS	100.0	90.8	91.7	73.3	68.1	84.2	84.3
Knows AIDS is caused by a virus	100.0	98.3	98.5	91.3	97.8	93.8	97.3
Beliefs							
Believes AIDS is caused by witchcraft	-	-	-	-	6.4	3.1	2.0
Believes AIDS is caused by poor nutrition	13.3	10.2	8.8	-	13.0	12.5	10.1
Believes AIDS is a punishment from God	6.7	39.0	2.9	-	42.2	58.1	25.0
Sources of knowledge (multiple responses)							
Television	56.7	48.3	72.7	22.7	9.3	81.2	50.9
Radio	96.7	70.0	76.5	26.1	7.0	78.1	61.3
Newspaper	27.6	26.7	64.7	19.0	9.3	43.8	35.6
Pamphlets/magazines	41.4	51.7	65.7	19.0	7.0	68.8	46.0
Doctor/nurse	93.3	66.7	52.4	80.0	60.9	77.4	67.6
Understands information from the source	70.0	88.3	79.4	69.6	97.9	84.4	83.0
Perceived modes of HIV transmission (multiple Responses permitted)							
Kissing	6.7	-	3.0	4.3	2.1	-	2.3
Using the same toilet seat as a PLWHA	6.7	-	1.5	-	-	6.7	1.9
Touching a PLWHA	3.3	3.3	9.2	-	2.1	3.1	4.3
Drinking from the same mug as a PLWHA	-	-	-	-	-	-	-
Breathing the same air as a PLWHA	-	6.8	1.5	-	2.3	12.5	3.9
Exchanging body fluids with those of a PLWHA	40.0	81.7	93.9	60.9	83.0	96.9	80.3
Having unprotected sex	96.7	91.7	95.3	87.7	97.7	93.8	94.0

Table 5.7: Types of informal help received by caregivers to PLWHA, by province and geographical area (percentages of "yes" responses)

Help source/ Type of help	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Receives help with daily caregiving							
Yes	80.6	75.4	68.1	23.3	42.0	57.9	59.3
Helper/help agency (multiple response permitted)							
Husband/partner	-	6.1	18.8	-	20.8	8.3	10.7
Child(ren)	16.0	36.0	36.0	28.6	37.0	8.3	36.1
Grandchild(ren)	4.0	10.0	20.4	-	12.0	8.3	11.7
NGO/CBOs (counsellors; home carers etc)	88.5	82.0	52.0	28.6	28.0	70.8	63.7
Community (nurse)	73.1	18.0	18.0	-	28.0	8.3	25.3
Nurse aid	32.0	2.0	16.0	-	-	-	9.4
Neighbours	8.0	51.0	24.5	-	12.0	16.7	25.7
Other relatives	8.0	42.0	22.4	42.9	34.6	25.0	28.7
Friends	52.0	38.0	14.3	14.3	4.0	17.4	25.1
Type of help received (multiple responses permitted) (n = 305)							
Financial	44.0	24.0	31.9	-	26.1	19.0	27.7
Washing the PLWHA	96.2	76.0	50.0	28.6	70.4	50.0	65.8
Feeding the PLWHA	100.0	82.0	54.9	84.6	62.5	71.6	75.9
Administering medication to the PLWHA	100.0	86.0	69.2	28.6	73.1	79.2	78.3
Transporting the PLWHA	68.0	57.1	62.5	57.1	50.0	41.7	56.9
Emotional/spiritual support	92.0	84.0	51.0	14.3	68.4	54.5	67.4

Cont/

Table 5.7 (continued):

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Perceived types of informal help needed by caregiver							
Training in caregiving	96.2	94.1	97.2	96.2	80.0	100.0	94.4
Information on HIV/AIDS	95.8	85.4	80.0	80.0	95.8	91.7	85.9
Guidance on how to care better for PLWHA	100.0	97.9	94.3	73.3	92.0	95.8	92.8
Guidance on how to access government assistance	92.0	72.9	91.4	93.3	79.2	52.2	82.3

Of these caregivers, almost two-thirds (63.7 %) indicated that they received such support from local NPOs. This pattern is common across all three provinces, but more so in non-urban settings. The majority were receiving help with daily activities such as administering medication (78.3 %), washing the PLWHA (65.8 %), emotional and spiritual support (67.4 %), and transporting the PLWHA to places such as health service points (56.9 %). Less than a third (27.7 %) was receiving financial assistance. The type of informal help that high percentages of caregivers reported they needed most was training in caring for a PLWHA (94.4 %), more information on HIV and AIDS (85.9 %), guidance on how to care better for the PLWHA (92.8 %) and guidance on how to access government assistance such as the child support grant (82.3 %). Overall, the caregivers thus expressed a need to be equipped with skills for daily caregiving to the PLWHA and for soliciting financial support from the government.

5.2.7 Formal care services for PLWHA

Table 5.8 gives a breakdown of the frequency of the caregivers' contact with health care service agencies and the perceived level of helpfulness of the health care providers. In the past 12 months, almost two-fifths (39.5 %) had taken a PLWHA to a health service facility

Table 5.8: Pattern of respondents' health care seeking behaviour for PLWHA in the past 12 months, and perceived helpfulness of service providers at the facility, by province and geographical area (percentage distribution)

Pattern of health Seeking behaviour	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-Urban %	%
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Frequency of visit to a health service							
2-3 times a Month	23.1	29.4	40.8	59.3	48.0	43.5	39.5
Once a month	61.5	45.1	50.7	40.7	28.0	47.8	45.6
< once a month	3.8	3.9	7.0	-	4.0	-	4.0
Other	11.5	21.6	1.4	-	20.0	8.7	9.9
Perceived helpfulness of health service providers							
Very helpful/helpful	100.0	98.0	84.3	85.2	93.3	91.7	91.2
Unhelpful/very unhelpful	-	2.0	15.7	14.8	6.7	8.3	8.8

more than twice a month, while slightly over two-fifths (45.6 %) had visited a facility once a month. Nine-tenths (91.2 %) who were visiting a health service point reported satisfaction with the help they received. This finding is at odds with findings of other studies conducted among clients of primary health service points in South Africa (Wouter et al.,2001; Westaway et al., 2003; Myburgh et al., 2005), which have shown consistently low levels of satisfaction with visits to a health care facility.

5.2.8. Disclosure of the PLWHA's status within the family and community

Table 5.9 shows the extent to which members of a caregiver's family were knowledgeable about the status of the PLWHA in the household. More than three-quarters of the caregivers (75.8 %) reported that some members of their family knew about the status. In almost two

Table 5.9: Numbers of members of the respondents' family and community knowledgeable about the PLWHA's status, by province and geographical area (percentages of "yes" responses)

Family members' Knowledge	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Family members* knowledgeable about PLWHA's status	96.2	92.2	69.0	33.3	80.0	87.0	75.8
Knowledgeable family member* (multiple responses permitted)							
Caregiver's spouse/partner	13.0	7.1	25.0	18.2	56.5	25.5	22.8
Child(ren)	50.0	70.2	62.3	63.6	77.3	50.0	63.3
Grandchild(ren)	4.5	31.9	31.5	18.2	60.0	15.1	28.7
Sibling	56.5	42.6	32.1	27.3	52.4	50.0	42.3
Caregiver's parent	-	8.5	14.0	-	35.0	21.1	13.0
Behaviour of knowledgeable family members towards PLWHA* (multiple responses permitted)							
Does not treat PLWHA differently	52.0	40.4	65.5	75.0	25.0	65.0	52.7
Is understanding and supportive	96.0	89.4	91.1	80.0	83.3	95.0	90.1
Avoids physical contact with PLWHA	8.0	-	3.5	-	16.7	15.2	6.0
Blames PLWHA for contracting HIV	6.2	4.9	-	-	-	23.5	3.8

Cont/.

Table 5.9 (continued):

Community Knowledge	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Extent that community members are knowledgeable about the PLWHA's status*							
One person	24.0	16.0	19.7	3.4	8.3	17.4	15.7
A few people	80.8	60.3	43.7	3.4	51.1	43.5	47.5
Widely known	44.0	33.3	50.0	13.3	34.8	43.5	38.2
None	-	6.0	13.6	17.2	9.1	8.7	9.7

* Table 5.9 indicates that the responses were provided by knowledgeable persons in the older carer's household

thirds of these cases (63.3 %), only the caregiver's children knew, but slightly more than two-fifths (42.3 %) reported that siblings were knowledgeable about the PLWHA's status.

No major differences in the extent of disclosure and knowledge of the PLWHA's status are evident across the provinces: neither between urban areas nor non-urban areas. However, it appeared that household members who were knowledgeable about the status were more protective of the PLWHA than members who were not aware of it. More than half the respondents reported that household members did not treat the PLWHA differently: nine-tenths (90.1%) were reportedly understanding and supportive.

However, disclosure of the PLWHA's status in the community was not as common: only slightly more than two-fifths of these caregivers (n = 227) indicated that "a few persons" in the community knew about the status; slightly over a third of 215 caregivers indicated that "everyone" in the community knew about it. The disclosure of a PLWHA's HIV status to the broader community therefore appears to be problematic for older caregivers, given the stigmatisation of the disease. Thus, non-disclosure may impede caregivers' access to much

needed support and solidarity from neighbours, such as practical and emotional support, and advice on where to find and how to access available local resources.

5.2.9 PLWHA's behaviour towards the caregiver

Older caregivers not only have to provide physical, material and emotional care to PLWHA, but may need to contend with abuse from the PLWHA. In addition, they may need to discipline co-resident grandchildren. Table 5.10 shows how caregivers perceived the PLWHA for whom they were caring behaved towards them: Of 231 respondents (the remainder did not respond to this item, seemingly in fear of repercussions from the PLWHA or to protect family dysfunction from the public eye), 14.7 per cent indicated that the PLWHA abused them verbally. Abuse of caregivers was more common in the non-urban areas of the Eastern Cape (29.4 %) and urban areas of the Western Cape (20 %) provinces, than in other settings.

Table 5.10: Caregivers' reported behaviour of PLWHA towards them, by geographical area (percentages of "yes" responses)

Type of behaviour	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Types of behaviour towards caregiver (multiple responses permitted)							
Shouts or becomes angry	12.0	29.4	8.5	10.0	20.0	4.2	14.7
Hits and throws things at caregiver	-	5.9	1.4	3.4	6.7	-	3.0
Accuses him/her of being responsible for illness	-	15.7	1.4	-	-	4.2	4.3
Refuses to talk to him/her	-	3.9	2.9	3.4	-	8.3	3.0
Refuses to take food from him/her	-	7.8	4.3	6.9	6.7	12.3	6.1

5.2.10 AIDS related deaths in the caregivers' households

Table 5.11 shows that an AIDS related death had occurred in slightly more than half of the sample households (55.1 %) in the past two years. More than two-thirds of the households in urban areas of the Eastern Cape (67.7 %) and KwaZulu-Natal (68.1 %) provinces had lost a household member to AIDS. Of the respondents who reported AIDS related deaths in their household in the past two years (n = 168), in almost two-thirds of cases (64.5 %) the deceased was the caregiver's child(ren). In two-thirds of cases (66 %), the deceased had lived his/her entire life in the house where he/she died. In three-quarters of cases, the deceased had contributed financially to the household. About a quarter of the carers (24.4%) had cared for the deceased for between four and seven months before s/he died. Of the caregivers who indicated where the PLWHA had lived and contracted the disease (n = 180), more than a half of the PLWHA (57.5 %) had lived in another city – and may have returned to the parent's home when they became ill. The majority of the caregivers (53.4 %) had first heard about the PLWHA's status from a health service provider, such as a doctor, nurse or other health provider in a clinic or hospital.

Table 5.11: Deaths in surveyed households due to AIDS in the past two years and the trajectory of the death/s, by province and geographical area (percentages of "yes" responses)

AIDS related death	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
AIDS related death in the household in last two years	67.7	53.8	68.1	53.3	52.2	28.9	55.1
Relation of the deceased to the caregiver							
Child(ren)	52.2	83.3	64.7	50.0	69.7	36.4	64.5
Spouse/partner	8.7	-	5.9	6.7	-	-	3.7
Grandchild(ren)	30.4	13.9	36.0	57.1	22.2	9.1	27.9
Other	-	-	-	3.9	-	-	3.9

Table 5.11 continued

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Deceased had lived with the caregiver all of his/her life	24.0	52.8	73.6	94.4	83.3	58.3	65.5
Deceased had contributed to the household financially	72.0	83.3	78.8	72.2	69.4	75.0	75.9
Number of months the caregiver had cared for the deceased							
Less than one month	4.3	-	5.9	5.6	17.1	36.4	13.8
1- 4 months	17.4	11.1	15.7	16.7	25.7	9.1	16.0
5-7 months	56.5	25.0	27.5	5.6	14.3	18.2	24.5
8-10 months	8.7	16.7	13.7	16.7	8.6	27.3	15.3
10+ months	13.0	13.0	25.5	16.7	34.3	9.1	18.2
Unsure	-	13.9	11.7	11.1	-	-	12.2
Place of residence when deceased was diagnosed with the virus/disease							
In another country	29.4	-	7.1	-	14.3	-	10.9
In a city	47.1	57.9	50.0	33.3	57.1	100.0	57.5
In a rural area	17.6	42.1	42.9	66.7	28.6	-	33.8
	-	-	-	-	-	-	-
Source from whom the caregiver learnt of the PLWHA's status ("yes" Responses)							
PLWHA	13.0	40.0	46.2	41.2	41.9	75.0	41.2
Nurses/doctor/clinic/ Hospital	82.6	48.6	53.8	38.9	50.0	41.7	53.4
Community health worker	47.8	22.9	13.7	17.6	10.3	16.7	20.4
PLWHA's partner	-	2.9	12.2	6.7	-	-	5.0

5.2.11 The situation of affected grandchildren in the households

Table 5.12 indicates the situation of co-resident grandchildren affected by AIDS and difficulties experienced by older caregivers in caring for these children. A total of 222 (72.8 %) caregivers were caring for a total of 616 grandchildren in their household – a mean of 2.7 children per household. Thirty-seven age eligible grandchildren were not attending school. In almost half of these cases, the caregivers indicated that the children were not in school because of a lack of money.

Two-fifths of the caregivers reported that their grandchildren were too young to attend school – and therefore needed full-time care. Of the 222 caregivers who had co-resident grandchildren, slightly more than three-quarters (76.7 %) reported that they themselves pay for the children's schooling; in KwaZulu-Natal, all caregivers were doing so. In the Eastern Cape urban area, more than half of the caregivers (59.3 %) reported that they and other family members pay for the schooling jointly. Caregivers gave various reasons why they were caring for the grandchildren, which ranged from there being no one else to care for them, or the children being "my blood" and the caregivers not being able to do otherwise.

Table 5.12: Grandchildren who co-resided with caregivers and school attendance of the grandchildren, by province and geographical area (frequencies and percentages)

Co-resident grandchildren	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non- urban	Urban	Non-urban	
	n	n	n	n	n	n	
Number of grandchildren in caregivers' households							
1	8	16	15	7	20	5	71
2 – 3	11	25	22	12	19	9	98
4 – 5	4	15	6	11	2	0	38
>5	1	6	2	6	-	-	15
Total	24	62	45	36	41	14	222

Cont/

Table 5.12 (continued):

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	n	n	n	n	n	n	
Number of age eligible grandchildren not at school							
1	5	3	6	8	1	4	27
2 – 3	-	-	5	-	-	-	5
4 – 5	-	-	5	-	-	-	5
> 5	-	-	-	-	-	-	-
Total	5	3	16	8	1	4	37
Reasons for age eligible grandchildren not attending school (multiple responses Permitted)	%	%	%	%	%	%	%
Lack of money	52.4	10.5	71.4	85.7	33.3	18.2	46.7
Child(ren) refuses to go to school	10.0	5.3	7.4	-	16.7	9.1	7.8
Too young	85.7	42.1	25.9	14.3	16.7	9.1	39.6
Has finished school	66.7	21.1	25.9	-	-	-	27.5
Is/are sick/disabled	-	-	7.1	-	-	9.1	3.3
Is/are HIV positive	4.8	-	40.7	-	-	-	13.5
Source of payment for grandchildren's schooling ("yes" Response)							
Caregiver	96.3	80.0	75.4	100.0	69.7	76.3	76.7
Other family members	18.5	6.2	16.4	6.9	11.7	2.6	10.5
Caregiver and other family-members together	59.3	12.5	27.5	7.1	9.8	-	17.8
Child support grant	7.1	24.6	14.5	14.3	8.5	26.3	16.4
An organisation (e.g. an NGO, church)	3.8	4.7	-	7.1	6.7	5.9	5.1
No school expenses	3.7	3.1	26.2	6.9	5.1	-	8.8

5.2.12 Perceived areas of caregiving in which the respondent needs support

Table 5.13 shows the areas in which the caregivers perceived they need support. The area in which they perceived they most needed support was money. More than nine in ten (94.6 %) perceived that they needed "a lot" of financial support. More than half (53.4 %) indicated a need for "a lot" of emotional support. A majority (51.2 %) reported they needed "a lot" of social support.

When asked which essential items relating to caregiving they found most costly, more than three-quarters (78.3%) of the respondents indicated school fees and school uniforms. More than two-thirds (67.1 %) reported that obtaining health care was the most costly expenditure item for them. Of the 297 carers who responded to the item on food provision, almost nine in ten (88.6%) reported that food was the most costly item. More than three-quarters (76.8 %) reported that buying clothes for their grandchildren was most costly. The majority of the caregivers perceived that they most needed help or support with food (90.4 %), followed by access to health care (89.4 %), counselling services (87.1 %) and physical care (65.4 %). Physical, or personal care refers here to bathing, grooming, dressing and feeding grandchild(ren).

Table 5.13: Perceived areas of caregiving in which the respondents need support and how much, and how costly essential items are for them, by province and geographical area (percentage distribution)

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-Urban %	
Total N	100.0 31	100.0 65	100.0 72	100.0 30	100.0 69	100.0 38	100.0 305
Financial support							
A lot of support	100.0	93.7	97.2	96.7	95.5	84.2	94.6
Some support	-	1.6	1.4	-	3.0	5.3	2.0
Don't need Support	-	4.7	1.4	3.3	1.5	10.5	3.4
Physical support							
A lot of support	62.1	51.6	55.7	56.7	30.3	18.4	45.8
Some support	31.0	28.1	41.4	36.7	45.5	47.4	38.4

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Don't need Support	6.9	20.3	2.9	6.6	24.2	34.2	15.8
Emotional support							
A lot of support	60.0	35.5	83.1	63.3	50.0	17.1	53.4
Some support	36.7	46.8	16.9	33.3	34.8	48.6	34.7
Don't need Support	3.3	17.7	-	3.3	15.2	34.3	11.9
Social support							
A lot of support	60.7	47.6	53.5	53.3	52.3	39.5	51.2
Some support	32.1	30.2	38.0	36.7	33.8	39.5	35.0
Don't need Support	7.1	22.2	8.5	10.0	13.8	21.0	13.8
Perceived most costly essential items, by extent							
School fees and uniforms							
Most costly	86.2	82.0	60.9	89.7	89.6	67.6	78.3
Costly	10.3	13.1	33.3	10.3	4.5	18.9	15.0
Least costly	3.4	4.9	5.8	-	6.0	13.5	6.7
Health care							
Most costly	78.6	72.6	83.1	73.3	68.7	5.9	67.1
Costly	17.9	19.4	16.9	26.7	26.9	32.2	23.0
Least costly	3.6	8.1	-	-	4.5	61.8	9.9
Food							
Most costly	96.7	96.8	83.1	80.0	97.0	70.3	88.6
Costly	3.3	3.2	16.9	20.0	-	16.2	9.1
Least costly	-	-	-	-	3.0	13.5	2.3
Clothes							
Most costly	76.7	87.1	56.5	80.0	95.5	61.1	76.8
Costly	23.3	12.9	31.9	20.0	-	25.0	17.7
Least costly	-	-	11.6	-	4.5	13.9	5.5
Transport							
Most costly	28.6	51.7	62.3	73.9	41.4	21.6	47.6
Costly	71.4	33.3	37.7	21.7	27.6	29.7	35.6
Least costly	-	15.0	-	4.3	31.0	48.6	16.7

Cont/

Table 5.13 (continued):

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Perceived major areas of need for help in caring for grandchildren ('yes' responses)							
Access to medical treatment	100.0	81.2	81.8	100.0	100.0	100.0	89.4
Counselling services	93.8	81.2	90.9	100.0	76.9	50.0	87.1
Food support	100.0	81.2	90.9	100.0	92.3	50.0	90.5
Physical care	87.5	73.3	51.5	50.0	81.8	-	65.4

5.2.13 Support received from the government with caregiving

Table 5.14 shows the respondents' perceptions of how sufficient the government support is that they receive. More than four in five (85.6 %) felt there is a need for government to provide more support to caregivers. Of these respondents (n = 247), more than nine-tenths felt that the government should provide money and a similar percentage felt that it should provide food parcels. Slightly more than four-fifths (82.6 %) wanted the government to support them by improving the condition of their dwelling: for example, by adding rooms such as a bathroom, and/or installing inside taps, a toilet and electricity, which would lighten the burden of caregiving on them.

5.2.14 Religious and social affiliations

Religion and contact with a place of worship played an important role in the lives of the older caregivers interviewed, and provided them with spiritual and emotional support. Table 5.15 shows that nine-tenths of the caregivers (91.1 %) belonged to a religious/faith body. More than half (55.9 %) visited a place(s) of worship every Sunday or more often. Slightly more than two-fifths (41.6 %) belonged to a community support group such as a senior centre or a luncheon club; more than half of the urban respondents belonged to such an organisation, but lower

Table 5.14: Caregivers' agreement with statements pertaining to the sufficiency of government support, and indication of types of government support needed, by province and geographical area (percentage distribution)

Agreement/ Disagreement	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Support is sufficient							
Agree	-	-	4.8	-	41.7	20.0	9.2
Disagree	100.0	100.0	90.4	100.0	50.0	80.0	88.2
Not sure	-	-	4.8	-	8.3	-	2.5
Support meets basic needs only							
Agree	100.0	70.0	15.0	20.0	100.0	45.0	47.5
Disagree	-	23.3	62.5	20.0	-	40.0	35.6
Not sure	-	6.7	22.5	60.0	-	15.0	16.9
Government must give more support							
Agree	100.0	86.7	82.9	50.0	100.0	95.0	85.6
Disagree	-	13.3	7.3	-	-	5.0	6.7
Not sure	-	-	9.8	50.0	-	-	7.6
Types of government support needed (multiple responses permitted)							
Food (e.g. food parcels)	100.0	98.3	88.9	73.9	95.0	100.0	93.9
Money (e.g. vouchers)	92.6	94.9	97.7	95.7	93.4	100.0	95.5
Home improvement (e.g. inside toilet, bathroom)	92.6	91.5	75.0	73.9	77.0	84.8	82.6

Table 5.15: Religious and organisational affiliation of the caregivers, by geographical area (percentages "yes" responses)

Affiliation	Geographical area		Total
	Urban	Non-urban	
	%	%	
Total	100.0	100.0	100.0
N	151	127	305
Belongs to a religious/faith body	87.8	95.5	91.1
Frequency of visit to a place of worship (n = 272)			
Every Sunday or more often	42.0	71.3	55.9
Two/three times a month	26.6	19.4	23.2
Once a month	12.6	5.4	12.9
Less than a month	2.1	0.8	1.5
Stopped attending because of caregiving	2.8	0.8	1.8
Belongs to a social Organisation			
Community support group (senior centre) (n = 298)	54.4	24.8	41.6
Burial society (n = 300)	40.6	52.3	45.7
Stokvel (community saving Scheme) (n = 291)	13.7	10.0	11.9

numbers in non-urban areas as fewer such facilities are available in these areas. Slightly more than a tenth of caregivers (11.9 %) belonged to a *stokvel* (a community savings scheme). Close to half (45.7 %) of 300 respondents reported that they belong to a burial society; in the non-urban areas, more than half (52.3 %) belonged to one. Membership of these types of societies may be viewed as a financial coping strategy in this population.

5.2.15 Discussion

The analysis of the survey data has shown that older caregivers experience multiple difficulties during the sickness of a PLWHA as well as after his/her death. Key findings from the analysis of the effects of the disease on affected households and older carers'

responsibilities were as follows: 1) The majority of the caregivers had particular vulnerabilities, as a result of their low socio-economic status, lack of access to help resources, little formal support and the burden of care. 2) The financial situation of the carers and their household was grim; apart from income from a social pension in the majority of cases, and from child support grants in some cases, no other support was forthcoming from the government for carers, such as a caregiving grant. 3) The carers reported poor health generally, aggravated by self-reported chronic health conditions (the conditions were not assessed clinically), hypertension, arthritis and stress in particular. Indeed, the conditions may have been induced or exacerbated by the strain of caregiving and associated responsibilities on the carers. 4) The majority of the respondents were knowledgeable about AIDS, its causation, and who is at risk of contracting the disease and how. However, about half in the non-urban areas believed that AIDS is punishment from God.

A belief that the disease is a punishment from God may be understood from a lay perspective as there being no explanation for the disease's causation, and the disease being neither curable nor reversible. People will therefore seek answers in the realm of spirituality. Within such a construction of the disease, AIDS is thus viewed as stemming from man's violation of God's moral order. Ancestors who are regarded as being closer to God than living mortals, and who are guardians of a clan's or a society's morality, are understood in the case of individuals with AIDS to be relaying God's anger at the man or woman for violating God's moral order, such as the institution of marriage or and indulging in promiscuity. God thus vents his anger at such wrong doers, which explains why they have contracted AIDS. The fairly widespread fatalistic belief of AIDS being punishment from God found in the non-urban sample in the Western Cape Province may be explained, partly, through possibly lower levels of knowledge about the disease in those areas, than in the other two provinces, where awareness campaigns about the disease have been more vigorous, owing to higher prevalance rates of the disease in those provinces, and the campaigns being undertaken earlier than in the Western Cape Province. Inhabitants of non-urban areas may also, by and large, have less formal education than their urban counterparts. A religious explanation for the causation of the disease may therefore have been more readily accepted or proffered as a response option for these respondents, than a scientific or medical explanation. It may be speculated furthermore that inhabitants of non-urban areas are more religious (and traditional) anyway than their urban counterparts.

Other key findings relating to the effects of the disease on caregivers' households and responsibilities are: 5) NPOs appear to play a significant role in providing support to older carers and their households, specifically through training on HIV and AIDS, advice on day-to-day caregiving, skills development and financial support. 6) The carers perceived that support from the government to help them with caregiving and related responsibilities was "non-existent." 7) Disclosure of, and stigma relating to HIV and AIDS are problems with which older carers must contend in their community.

A comparison of the data across the three provinces showed the following differences and commonalities: Almost all the caregivers (and by implication the members of the households) were South African (97.7%). All the participants in the non-urban area of KwaZulu-Natal headed their household, compared to 87.7 % and 86.8 % in the Eastern Cape and the Western Cape provinces, respectively – which finding is consistent with the majority of household studies carried out in South Africa (see Makiwane, 2004; Ferreira et al., 2001; Orner, 2006). However, a surprising finding was that two-thirds (66.7%) of the caregivers were married, which is atypical in older women in South African settings, especially in rural areas. An explanation for this anomaly may lie in polygamous marriages, which are common in KwaZulu-Natal, resulting in women in a polygamous relationship heading their household even though married.

STATSSA 2007 survey data indicate that the Eastern Cape Province is socio-economically the most under-developed of the three study provinces, with only 72 % of households having access to piped water, compared to 82 % in KwaZulu-Natal and 98.9 % in the Western Cape. The Eastern Cape also has the highest percentage of households (19.5 %) without a toilet (a similar percentage was found in the present study), with percentages of 7.3 and 5.5 for KwaZulu-Natal and Western Cape, respectively. Similarly, the study found only 68.8 % of houses in the Eastern Cape had electricity, compared to 73.4 % in KwaZulu-Natal and 94 % in the Western Cape. However, the Eastern Cape had the lowest percentage of households living in informal dwellings (7.1%), followed by 8 % in KwaZulu-Natal and 16.8 % in the Western Cape. Informal settlements are more common in the Western Cape due to a high rate of in-migration to the area to seek employment and education opportunities, and under-provision of housing infrastructure (see e.g. Kok & Collinson, 2006).

The respondents' poor socio-economic status undoubtedly makes caregiving more difficult for them. Their particular vulnerability was evident in several indicators in the analysis: socio-economic and health related indicators, and a lack of support, in particular. This finding corroborates similar findings in other studies in SSA countries (see. e.g. Makiwane et al., 2004; May, 2003; Mba, 2003; WHO, 2002a). The housing circumstances of the majority of the carers were reported to be poor and to hamper caregiving. The majority used a pit latrine, obtained water from a communal tap, and complained about cramped living space. Some in the rural areas of the Eastern Cape get their water from unprotected source such as rivers or pond putting them and their dependents at risk to waterborne disease such as cholera. The majority verbalised a need for support from the government to improve their dwelling, which they perceived would help them to cope with the burden of caregiving. Poor environmental and housing infrastructure, or lack thereof, in these and other areas persists 16 years after the advent of democracy, and despite promises of the government to improve the quality of life of all citizens. Nonetheless, what is salutary is that almost two-thirds of the carers received an old age pension from the government.

The financial situation of the carers' households was equally dire. Besides income from a social pension in two-thirds of cases, the households received little other support from the government, other than a child support grant in some cases. Financial support from other family members living elsewhere was limited and not dependable. Only some carers engaged in income generating activities, such as petty trading, to supplement the household's income; the majority did not, or were unable to do so because of caregiving responsibilities. The households' and carers' dire financial situation prompted the majority of the respondents to call for the government to provide money or food vouchers to persons such as them. Even though PLWHA with a high level of morbidity are eligible for a disability grant, none of the households was in receipt of such a grant. Disability grants could provide much needed relief and a safety net for such households.

The respondents were asked to indicate which items on a list of essentials were most costly and least costly for them. A reason for asking them to rank their household consumption and expenditure needs in this way was to establish areas of major financial burden for respondents relating to caregiving. The results could inform recommendations on areas in which support intervention is most needed. In interpreting this data, the frequencies for "most costly" items were regarded as most important. The areas of need, in rank order, were food

(except in non-urban KwaZulu Natal), clothing, health and transport. In the Western Cape, health and transport were least important owing to residents' relative easy access to these services in that province.

Although the older carers were making a valuable contribution by shouldering the burden of care in their household, assuming such responsibility often came at a great cost to them. Apart from the direct financial costs of caregiving, the burden of care affected the carers' health adversely. Older carers, the majority of whom reported having chronic health conditions, merit special attention at health care facilities: not only to optimise their functioning, but to sustain their care contributions as well (Ferreira et al., 2007). Earlier studies have provided evidence moreover of adverse psycho-somatic disorders in older carers as a result of caregiving (see Burton, 1992; Fuller-Thomson & Minkler, 2000; Kelly, 1993; Minkler & Roe, 1993; Shore & Hayslip, 1994).

The respondents' level of knowledge about AIDS was surprisingly high. Nonetheless, a belief that AIDS is punishment from God was fairly widespread in non-urban settings, and indicates a fatalistic attitude, which may be an area of concern in the national fight against the epidemic. This finding concurs with the results of the WHO (2002a) study among older caregivers in Zimbabwe. Hence, by implication, despite the body of information about the disease that is available, a sizeable proportion of the older population seemingly believes only in divine intervention as a solution to the spread of the disease. For this reason, a strong faith in God among the carers may be a coping strategy, in the absence of formal support, to deal with affliction in their household and the burden of caregiving.

Non-profit organisations are clearly playing a crucial role in supporting older carers on a continuing basis. A high proportion of the carers reported receiving assistance from NPOs. The lead taken by NPOs in supporting affected older carers has been reported by Knodel and colleagues (2006) (Knodel et al., 2006) in southeast Asian countries. The lack of formal government support to older carers in South Africa is reflected in the absence or underdevelopment of appropriate policy and programme responses to meet the needs of older carers.

The respondents were virtually unanimous that support provided by the government is insufficient to alleviate the strain of caregiving. Finding of studies conducted by Knodel and colleagues (2006) in Cambodia and Thailand, other highly affected developing countries, in

this regard are similar. In the present survey, the older carers indicated that they needed "a lot" of support in the following areas: Money to buy food and other basic necessities; respite care or physical support with daily activities such as feeding, washing and providing medicine to PLWHA; emotional support; and social support. The government does not provide support in any of these areas. Presumably it relies on NPOs to do so. Moreover, where the government does provide support to individuals and families affected by AIDS, none of it is targeted at older carers, particularly in non-urban areas, which substantiates the carers' perception that they are excluded from support programmes.

Apart from caring for PLWHA, the majority of the respondents were caring simultaneously for grandchildren affected by the PLWHA's illness. Although two-thirds of the carers received a social old age pension, and in several cases a child support grant, or several such grants, they still reported experiencing serious financial difficulties. Without formal support, numerous carers may have no option but to prolong the interruption of economic activities after the death of the PLWHA, as they must continue caring for young orphaned grandchildren. As the HIV and AIDS crisis in South Africa is unlikely to abate soon, a growing number of young children will be orphaned in the coming years and a similar growing number of older persons will be burdened with caring for them. In most cases the carers will have to provide psychological and emotional support in addition to physical and material support to the children. Indeed, the carers in the survey indicated that they themselves need "a lot" of emotional support as well.

Not surprisingly, stigmatisation of the disease was found to be a problem in most of the communities in which the survey was conducted, which negative attitude is counterproductive to affected households and family members, and an obstacle for them in seeking help resources. More positively, family members of PLWHA were reported by the respondents to be supportive of the PLWHA, which suggests that anti-AIDS stigma interventions may be accepted at a family level, which will help to strengthen family resilience against the stigma. The radio emerged as a primary source of information on AIDS, which presents a useful option for addressing HIV and AIDS among older carers.

Although a high level (91.2 %) of health seeking behaviour was found among the carers, studies conducted in populations of similar socio-economic background in South Africa tend to report the opposite – as pointed out earlier. Moreover, in addition to seeking health care at

mainstream public health services, the carers also consulted "alternative" health providers (typically, traditional healers). A belief in the efficacy of traditional healers, and consultation of them, were mentioned in case study # 4: "…and I know of traditional healers who can cure sexually transmitted infections such as *gcusula* (gonorrheoa). .." Despite the new knowledge she had acquired, the subject continued to believe that AIDS is a form of *gcusula*. Health care seeking behaviour of persons infected or affected by HIV/AIDS documented in a study in Ghana (Awusabo-Asera & Anarf, 1997) also found that help was sought from both mainstream and traditional health services, either concurrently or serially. However, a study conducted in India showed that infected and affected individuals tended to seek health care from alternative healers, more covertly, as a way to "escape" stigma and discrimination (Mahendra et al., 2002). An identification and understanding of attitudes towards the disease and barriers to seeking health care should therefore be considered in the design and implementation of programmes for infected and affected persons.

Also striking in the findings is that few men (8.8 %) were primary care providers. The majority of studies conducted on caregiving to PLWHA and OVC have shown that caregiving is essentially a women's responsibility and that males tend not to participate in caregiving directly (WHO, 2002; Ferreira et al., 2001; Schatz, & Ogunmefun, 2005). However, this view has been challenged by feminist theory advocates (Canfield, 1997). In the literature on HIV and AIDS management at a household level, scant attention has been given to men as primary caregivers – to both PLWHA and OVC. Men have typically been viewed as family and household providers, or as providing a supportive role, but not as a primary carer. Although only a few men were interviewed as primary carers in the present study, older men should nonetheless be regarded as valuable players in caregiving, even though they may lack the caregiving experience that older women have, and may not be expected culturally to provide care. HIV and AIDS intervention programmes thus need to take into account that some older men do render care to PLWHA and OVC, and may indeed do so increasingly, and should include them in interventions.

Another consideration is that caregivers to PLWHA and OVC are likely to suffer health problems associated with the stress of caregiving, which may be especially true for male caregivers (see e.g. Kespichyawattana & Van Landingham, 2003). Moreover, male caregivers tend to seek health care for such ailments later than female caregivers. Hence, it is important that interventions take these considerations into account as well – and help male caregivers to

understand possible consequences of caregiving for their health, to know where to access health care, and to know how to take care of their health. Finally, male caregivers should not be overlooked in that they constitute a positive role model for other men in their communities: in challenging culturally defined stereotypes of male and female specific roles within families, and contributing to the care management of the epidemic.

Other similarities and differences across the provinces were as follows: Slightly more than two-thirds of the caregivers had lived in the area in which they were interviewed for ten years or longer, which suggests that they enjoy a strong social network (see table 5.3). A surprising finding, indicating differences, was that 58 % of non-urban respondents in the Western Cape believed that AIDS is punishment from God, compared to only 3 % of respondents in urban areas of KwaZulu-Natal (see table 5.6). This difference is noteworthy, highlighting possible fatalistic views about the disease held in those areas, and suggests that HIV and AIDS information campaigns should be strengthened and adapted accordingly.

Although the majority of studies on caregivers report poor self-reported health status, the present study's data differ. Only 40.9 % of the respondents rated their health status as similar to that of their peers, while 35.1% reported that their health was worse (than that of peers). Heterogeneity among carers in this regard should thus be recognised.

Findings of analyses of the data suggest that more needs to be done for older carers on a number of levels. The findings are certainly relevant to the development of old age support policies in South Africa, particularly to benefit older caregivers. The findings also underscore a need for intergenerational support in households affected by AIDS in which co-resident older persons are caregivers. Not least is the poor socio-economic status of the majority of these households that needs to be addressed, and the combined effects of caregiving and poverty ameliorated. Interestingly, the results indicate that older caregivers in urban areas are more likely than their counterparts in non-urban areas to lack sufficient money for basic expenses – in part due no doubt to a higher cost of living in urban areas. Moreover, urban dwellers need to earn income to be able to purchase items to meet basic needs, such as staple foods and energy, whereas rural dwellers may to an extent rely on subsistence agriculture, like working their fields and raising stock (sheep, goats, chicken) to feed themselves and their household.

The respondents in the Eastern Cape appeared to have better access to social support than their counterparts in the other two provinces. Social grants and welfare services appear moreover to be targeted effectively at poor households in this province. A STATSSA (2008) survey indicated that of the three study provinces, the Eastern Cape has the highest percentage of welfare recipients (16.6%), compared to KwaZulu-Natal (12.6%), and the Western Cape (8.2%). However, HIV and AIDS is the leading cause of death in both men and women in the Eastern Cape; in 2000 Bradshaw et al. reported an overall rate of 20%, and AIDS being the leading cause of death in children younger than five years. Nonetheless, since 2005, the provincial government has established substantial infrastructure and services to fight the disease.

A high proportion of PLWHA in non-urban areas of the Eastern Cape (61.3 %) had indeed learned of their status when their caregiver had taken them to one of these accredited health service centres (table 5.8). The majority of these caregivers had also found the health care providers to be helpful. This finding contrasts with the low reportage of the PLWHA status from the other two provinces, and may be attributed to the fact that carers in the Western Cape and KwaZulu-Natal provinces have more options (agencies/facilities) available to access information about the PLWHA's status, such as, private health institutions, general practitioners and voluntary counsellors at VCT clinics. On the other hand the carers themselves in the Eastern Cape Province appeared more reluctant than counterparts in the other two provinces to use health services – possibly due to poor and ageing infrastructure (e.g. roads, buildings and telecommunications). Poor roads make travelling and access to critical services difficult for the majority of older residents, especially in non-urban areas. However, difficulties experienced at service points may also contribute to a reluctance to seek care at the centres. Staff shortages and staff attitudes may be problematic, anecdotal evidence of which has been reported recently (2008/2009) in the media, as well as shortages of medications and perceived unhygienic facilities.

The matter of PLWHA's access to anti-retroviral therapy is important, in that at the time of the study, major challenges were being experienced in the roll-out, or implementation of the ARV programme countrywide – except in the Western Cape Province. PLWHA's access to the treatment was not assessed in the study, as the results would not have provided reliable information in terms of comparative accessibility. Moreover, according to the Department of

Health's HIV/AIDS treatment protocol, PLWHA are only given ARV therapy when their CD4 cell counts falls below 200, and CD4 count values were neither measured in the survey.

The findings of the analysis of the survey data offer measurable outcomes to inform the design of policy responses and interventions that support older caregivers, as well as their sick adult children, and orphaned and vulnerable grandchildren holistically. To a large extent, the survey findings confirm findings of other, albeit smaller and geographically confined studies in this subject area, but also extend notably on earlier findings

PART 2: CASE STUDIES DATA

5.3 ANALYSIS OF THE CASE STUDIES DATA

5.3.1 Introduction

Follow-up in-depth interviews were conducted by the researcher with ten randomly selected older carers who were interviewed earlier in the survey. For logistical reasons, the households were all located in the Western Cape Province, in both urban and non-urban settings. Four households were identified in Khayelitsha and two in Nyanga (urban settings), two households in Macassar and two in Robertson (non-urban settings). The data gathered was categorised by the researcher. Six categories or domains were selected to classify the coded data, which provided an analytical framework for the qualitative follow-up study. The six domains, which were similar to domains covered in the survey (see sub-sections 5.2.2 to 5.2.8).

Pseudonyms are used for all carers whose responses are referred to the text below. The pseudonyms are used similarly in the ten case studies shown in Annexure 7.

5.3.2 Analysis of the data

5.3.2.1 *Socio-demographic profile of the sub-sample*

With the exception of one carer, who was 59 years old and not eligible for an old age grant, all the carers interviewed were 60 years and over and received a social old age pension. The mean age of the carers was 68 years. All were grandmothers and, on average, had four co-resident grandchildren. All were primary caregivers to the PLWHA and grandchildren. The

social pension was their main source of income. Most were unemployed, owing partly to caregiving responsibilities to the PLWHA and grandchildren, and partly to their own ill-health. The majority was widowed. Eight had received primary education and none had an educational level beyond standard 10; two had no schooling. A number had not completed school owing to a lack of financial resources and/or early marriage. In eight cases, the PLWHA for whom the carers were caring was their adult child; in two cases it was a grandchild.

5.3.2.2 *The carers' health status*

Virtually all the carers interviewed had one or other chronic ailment which was either being treated or was untreated. Common ailments were stress, depression, insomnia, hypertension, diabetes and arthritis, all which can complicate caregiving and limit a carer's full potential to care.

Some carers felt that their caregiving responsibilities aggravated their health condition(s). Mrs Nino, 72 years old, explained the effects that caring for a son with AIDS had on her health: "My son's illness gives me a lot of worries, on top of which I suffer from high-high [high blood pressure]. I sometimes forget to take my diabetes medication. I am very worried that with my worsening illnesses and old age I might die first and I do not know what will become of my child and grandchildren when I am no longer around." What worries Mrs Nino even more is that she suspects that one of her grandchildren might be infected with the HI virus, as he shows most of the symptoms that his father presented with, such as a persistent cough and physical wasting. This concern places a heavy strain on her health (Case study # 1).

Mrs Kamanga, 59 years old, had similar concerns. Widowed, she had lived in various townships around Cape Town, but mainly in Khayelitsha. She was living in a small four-roomed shack house with four other people when interviewed. She explained that: "My household problems are too much for an older person like me. The problems I face in this house affect my health badly. I think I am suffering from a lot of stress, although the doctors at the clinic have not detected it for now. They are only giving me treatment for hypertension, arthritis and sugar diabetes" (Case study # 4).

Mrs Zizo, 65 years old, described the effects that caregiving was having on her health: "Now I have developed a new thing, I spend sleepless nights thinking about this 'bad thing' [HIV and AIDS] that has happened in my house. I suffer from constant headaches ever since I was told that my daughter has been infected by HIV. My diabetes condition has become worse although I am taking treatment for it. I believe that my health has moved from bad to worse because of the situation in this house" (Case study # 5).

Sleeplessness is a condition from which several caregivers suffered, although not all mentioned it explicitly. Mrs Rory, 73 years old, believed that caregiving relating to HIV and AIDS affected her sleep badly: "My granddaughter's health situation is putting a lot of stress on me, now I have a funning and unusual thing, I wake up at night … and have to take sleeping tablets to be able to sleep at again. Sometimes I cry for no reason." She prays a lot about her granddaughter's condition and hopes that she will be healed one day, as she believes in miracles, she explained (Case study # 9).

A health-related situation reported in all the case studies was that caregiving is not only a physical burden but triggers illnesses and exacerbates existing ailments. New conditions triggered in this way include sleeplessness, worsening hypertension and headaches. Curiously, the majority of the carers reported positive experiences with health service providers: they found them helpful, as was shown in analyses of the survey data, but which is in contrast with findings in other local studies (e.g. Joubert & Bradshaw, 2000). However, some carers who suffered from diabetes felt it was unrealistic for doctors to prescribe special diets for them, as they could not afford to buy the special foods needed with their meagre pension money. A carer reported that she was afraid to take her grandchild to a clinic to be tested for HIV, even though she suspected the child might be infected with the HI virus, as the nurses would "scream" at her if she brought a child without knowing what was wrong. "Some of the nurses at the clinic can be very harsh." By and large, the majority of the carers carried out the role of primary caregiver to a PLWHA and grandchildren despite their advanced age, poor health and lack of support; as a consequence, some felt that their contributions were limited.

5.3.2.3 *The carers' knowledge of HIV and AIDS*

In general, most of the carers knew what HIV and AIDS were: they explained that HIV is a germ (virus) that results in AIDS. Most reported that AIDS manifests in various medical

conditions such as tuberculosis, pneumonia and skin lesions (sores on the body), or a combination of these conditions. They also knew that a PLWHA becomes sick over several months before succumbing to the illness. Most reported that the PLWHA apparently contracted the illness through unprotected sex. The majority had acquired knowledge about the disease at an NPO to which they belonged and after their child had been diagnosed with the disease. However, prior to joining the NPO most had lacked knowledge of the disease, or had a confused and fatalistic idea of what the disease was. Volunteer workers at their community NPO had taught them what they now know.

Mrs Kamanga, 59 years old and widowed, who resided in Khayelitsha, explained: "…AIDS can be cured like any other sexually transmitted disease. And I know of traditional healers who can cure sexually transmitted infections such as *gcusula* (gonorrheoa)." She continues to believe that AIDS is a form of *gcusula,* despite the new knowledge she has acquired about the disease (Case study # 4). Mrs Noor, 76 years old, commented fatalistically as follows: "[I]… believe strongly that it is a punishment from God to wrongdoers and one can't do anything about it. … the bible says there will come a time where there will be incurable diseases because people have sinned in the eyes of God." Mrs Noor also felt that the local Day Hospital needed to supply carers with enough material such as gloves and plastic aprons, as she had struggled a great deal trying to obtain gloves when she was caring for her daughter, now deceased (Case study # 10).

A common feature in the case studies of both the urban and non-urban based carers, as far as HIV and AIDS are concerned, was that prior to joining an NPO the majority had believed that the disease is only contracted by young people, specifically promiscuous youth, and that older persons are not at risk of infection. Mrs Tibo, 60 years old and residing in Macassar (a non-urban area), whose daughter was diagnosed as HIV positive in 2003, explained: "I did not believe [it] when I was told by a doctor about my daughter's status. I thought that HIV is contracted by persons who sell their bodies [sex workers] for money, and those who 'shoot' [intravenous drug users], and not people in marriage or in steady relationships like my child" (Case study # 7). Similarly, Mrs Bidi, 66 years, resident in Nyanga (an urban area), did not know what was wrong with her daughter before her death, nor did she know about AIDS, who is at risk of contracting the disease and whether older persons can be infected with the virus. She did not know that a carer should wear gloves and other protective equipment when attending to a PLWHA. Such information, she pointed out, is not shared on the radio.

Nonetheless, it was her view that wearing protective equipment to wash her own child would be inappropriate and indicate a rejection of her own "flesh and blood," which would be frowned upon culturally (Case study # 8). A reluctance of older carers to wear gloves in these cases was also identified in a WHO (2002a) study in Zimbabwe.

A majority of the carers had learnt about HIV and AIDS from the radio, while some had acquired knowledge from sources such as television, health professionals, and pamphlets and magazines. Indeed, the sources of information on HIV and AIDS that the majority of older persons relied on may have been insufficient to equip the carers to protect themselves and those in their care, such as their grandchildren.

5.3.2.4 *Formal and informal support available to the carers*

Although most of the carers received a social old age pension, only a few received a child support grant for grandchildren in their care. None though received any formal support to help them to care for a sick person afflicted with AIDS. Most described the pension as their main source of income. Some referred to it as *inkam-nkam* and *indodla*, which translated means "that which feeds me". Mrs Tiki-Tiki told that: "I cannot wait for the end of the month so that I can receive my *inkam-inkam* to address my household problems" (Case study # 2). Although the regular monthly pension provided a social safety net for the carers, most had misgivings about the amount of the benefit, and explained, for example, that "…my husband's pension and mine are not enough to support three school-going children, two adults and a sick person who needs special care" (Case study # 2).

Carers specifically mentioned a lack of financial resources and how HIV and AIDS were impoverishing their household. Some were trying to augment their income by selling perishables in their communities, such as fat cakes, sweets, fruit and vegetables. Mrs Zozo had this to say: "…it is because of the little things that I sell to make ends meet, that helped me to put bread on the table and send my grandchild to school. … I am concerned that she might not finish school because of scarce financial resources because of this disease…" (Case study # 3).

Mrs Zozo noted that: "…sometimes I have to borrow money from money lenders [loan sharks], and they charge very high interest rates and sometimes confiscate one's ID [identity document] until one pays back the money in full" (Case study # 3). On the other hand some carers identified attractive features of the pension as being its regularity and dependability:

they could rely on the same amount being paid to them on the same day each month, which afforded them a sense of financial security.

The carers were asked how the government might support them with their caregiving responsibilities. The majority indicated a need for money, to help them to buy nutritious foods for the PLWHA, to transport him/her to health service points, and to meet grandchildren's schooling related needs, such as books, uniforms and fees. Some said they would like to have a better house, with more rooms, electricity, and a flush toilet and piped water inside the house, which would help them to provide better care. Few carers mentioned support in the form of information and education on HIV and AIDS, but one suggested that the government should include older persons in HIV and AIDS prevention campaigns, which should not only be for young people.

All indicated that they received informal support from NPOs in their residential area, the most important support provided being education and information on how to care for a PLWHA. Mrs Rory, 73 years old, explained: "I was told by the home based care volunteers about HIV and AIDS. They also told me that older persons can contract the disease if they are sexually active and do not protect themselves by using condoms" (Case study # 9). Some indicated that NPOs supported them by equipping them with income generating skills that enabled them to supplement the income they received from the pension. None indicated that they received help from family members and neighbours. However, some respondents in the survey indicated that they received support with caregiving from family members, especially their adult children.

5.3.2.5 *Disclosure of the status of the PLWHA to the caregiver and stigma*

A reluctance to disclose the status of the PLWHA for whom a carer was caring was common. Some distanced themselves from HIV and AIDS and gave it other labels, such as "this problem" and "this thing." Mrs Nino explained that she had not disclosed the PLWHA's status to neighbours, as people would gossip about her family because of "this thing". A fear of rejection and isolation of her family or household in the community was the reason that most carers had kept quiet about the disease (Case study # 1). Other carers' concerns were that grandchildren might be harassed by other children in the neighbourhood. Some were concerned about being judged to have failed as parents by not teaching their children good morals. Mrs Zizo explained: "…I am worried that people will gossip and judge my parenting

skills…" (Case study # 5). Nonetheless, one carer felt there was merit in disclosing the disease: "I tell those who want to know about my grandchild's illness and telling people the truth has helped me overcome my fear [of it]" (Case study # 10).

Many carers felt that disclosing the illness to other family members and/or neighbours might result in discrimination against, or isolation of the caregiver's family. HIV and AIDS related stigma is strong in some communities, especially where HIV and AIDS stigma is gender based. HIV positive women who disclose their status are treated more harshly than HIV positive men. Mrs Tiki-Tiki, who resided in Khayelitsha, told that: "One other thing that made me reluctant to disclose my daughter's status to other people is that, in this township, people with AIDS are treated very badly, especially women are discriminated against and sometimes they are killed violently by some community members. Some people still believe that women are spreading HIV" (Case study # 2). Seemingly, in most of the communities in which the older carers resided, people did not talk openly about HIV and AIDS, which fostered stigma further.

A sentiment that stigma is a greater problem for HIV positive women than for male counterparts has been identified in other studies in South Africa (e.g. Petros et al., 2006). Stigma and discrimination against female PLWHA are barriers to the women's accessing free VCT and PMTCT services. Mothers who are HIV positive find it difficult to comply with medical advice to formula feed their infants, through a fear of having their HIV status exposed. Older persons, especially older women, are often targets of AIDS stigma. Mrs Kamanga, 59 years, pointed out that: "… another thing is that people in my area still keep old ideas about illnesses, especially when someone does not get cured, people believe the person has been bewitched and fingers might point at me." Mrs Kamanga added that her son has already accused her indirectly of being the cause of his illness (Case study # 4). An association between HIV and AIDS, witchcraft and older persons is common in some parts of SSA, including South Africa. Older persons are accused by members of their community of being responsible for inexplicable events or ills that befall a community, such as people manifesting AIDS, and in some cases are forced to flee their homes (see Chapter 2). Old age and HIV and AIDS stigmatisation are thus issues that older carers have to contend with in their household and community.

5.3.2.6 *Co-resident grandchildren and caregivers' concerns*

Most carers viewed caregiving as an obligation to a relative in need: care recipients are family members who need to be cared for on an ongoing basis. In general, the majority viewed their grandchildren as being an integral part of their lives and as such they had a duty to care for them. Some had a positive vision for their grandchildren's future. Mrs Zoe explained: "I want my grandchildren to remain at school until they finish school and live a better life than mine which is full of difficulties…" (Case study # 6).

Failing to fulfil an obligation to keep grandchildren in school would imply a failure on the part of the carer to protect, nurture and provide for the future of her own. Caregiving for grandchildren is demonstrated most prominently in the carers' ability to provide four basic necessities for survival: food, health, clothing and shelter. Mrs Tibo told: "… I need to provide them with food, [meet] school expenses, buying clothes … and providing a home for them" (Case study # 7). Although the caregivers may have been concerned about daily responsibilities that challenge their caregiving, such as discipline of grandchildren, most tended to be future-oriented and displayed proactive approaches in seeking support to help them to care for grandchildren. The majority asked for financial assistance so that they could keep their grandchildren in school and the children would not fall prey to HIV infection from older men who buy them expensive items in exchange for sex. "… child(ren) might come under bad influence, as most girls of her age in the community land up stopping going to school because of pregnancy. Some of the girls simply leave school to associate with older men, who buy them nice clothes, cell phones and make them pregnant or give them sexually transmitted diseases" (Case study # 7).

Two carers felt that the government should involve older persons in programmes aimed at combating HIV and AIDS. "…government should also involve older persons in HIV and AIDS related matters, and provide them with enough materials such as gloves, plastic aprons to protect themselves from becoming infected." (Case study # 1) One felt that the burden of caregiving would be reduced if the government supported carers by exempting them from paying school fees for orphaned and vulnerable children.

5.3.3 Discussion

An analysis of the data collected for the case studies showed that the respondents by and large reported similar problems and experiences relating to caregiving – both in urban areas and non-urban areas. The case studies ended when it became evident that no new information was forthcoming (see section 5.3.2) – in either the urban or non-urban settings. Hence, saturation was deemed to have been reached with the case studies. Content analysis of the data was then carried out, rather than using a grounded theory approach.

A distillation of the findings showed that HIV and AIDS affect older caregivers on several levels: 1) Caregiving compromises their mental and physical health; 2) they suffer emotional problems; 3) they must forego employment opportunities and thus livelihoods because of caregiving responsibilities; 4) they fear stigma and discrimination; 5) some hold fatalistic beliefs about the disease; 6) they contend that the government should support caregivers by providing financial support in addition to their old age grant; and 7) they appear to render care in anticipation that their grandchildren may reciprocate care and support in the future From a social exchange theoretical perspective, such anticipation is referred to as delayed reciprocity.

Some carers reported that the strain of caregiving resulted in new ailments, such as sleep disorders, constant headaches, stress and depression. Several suffered from physical ailments such as hypertension, arthritis and diabetes. Some reported health conditions that had not been diagnosed and/or were being treated by a doctor. Some feared antagonistic, or "harsh" treatment from health professionals at public health care facilities. Hence, emotional health problems that they suffered would conceivably be debilitating, and reduce their ability to render care and cope. Indeed, it is possible that the chronic health conditions that several carers suffered could cause physical disability and even lead to an early death.

Caregiving not only has a negative effect on an older person's health, therefore, but affects his/her ability to engage in income generation. Some carers reported that they had to give up their job to be able to care for the PLWHA and grandchildren full-time. Indeed, such a disruption in an older person's financial coping strategy could worsen his/her already vulnerable situation. Fear of HIV and AIDS stigma was common among the caregivers. Some reasons advanced for a fear of stigma were that people might gossip about the family, because of "this thing" (disease) in the household. Even worse, grandchildren may be

discriminated against, and their lives put at risk, or other children might not play with them, which would cause unnecessary misery for the children. Such fears indicate that HIV and AIDS related stigma does not stop with the PLWHA but affects all household members. Labelling HIV and AIDS as "this thing" indicates a frustration and a sense of helplessness of carers who carry the burden of caregiving.

The myriad problems presented by the epidemic and caregiving responsibilities clearly induced a sense of despair in the carers. Some held fatalistic beliefs about the disease, possibly as a way of coping, such as AIDS being punishment from God to wrong doers, and only God being able to bring a solution to the problem of AIDS.

There were no discernable differences in caregiving patterns and problems between caregivers in urban settings and their non-urban based counterparts. However, it was evident that the carers could not cope with the burden of caregiving on their own and needed formal support. Some suggested, for example, that the government should consider exempting older caregivers from paying school fees for their school-going grandchildren. In the absence of formal support, older carers cope with their burden as best they can; the degree of informal support they receive is variable, but support that some receive from NPOs is fairly considerable. They were of the opinion nonetheless that they now need formal support commensurate with the caregiving demand on them. Thus, by implication, if caregivers are sufficiently supported, they will be better able to care for affected grandchildren until they reach independent age.

Hence, older carers interviewed in the case studies demonstrated by their actions that they have a contribution to make as partners in the fight against HIV and AIDS – if they are secure, have improved self-esteem and feel confident. The carers demonstrated their resilience and compassion, but they were buckling under the strain of caregiving and the pain of not being able to provide adequately for their grandchildren. Nonetheless, NPOs, according to the carers, do commendable work to ease the carers' situation: especially in providing information and training on HIV and AIDS, transferring skills carers, and supporting carers emotionally and materially.

PART 3: KEY INFORMANT INTERVIEW DATA

5.4 ANALYSIS OF THE KEY INFORMANT INTERVIEW DATA

5.4.1 Introduction

Eight persons were identified as key informants in the three provinces, on grounds of their knowledge of government policy and planning on HIV and AIDS, and were interviewed by the researcher using a specially constructed interview guide. Of the eight informants, five held positions in government and three managed an NPO that served older persons. In each province, two senior government officials in provincial departments of Social Development and Health, respectively, were identified, but one was unavailable for an interview as agreed. Interviews were then consequently conducted with only five government informants.

The data from the key informant interviews were analysed in the following domains: 1) Knowledge of and availability of policies and programmes to support older caregivers; 2) the role of the provincial government department or NPO in providing support to caregivers; 3) older persons,' or their representative bodies' participation in policy formulation processes; 4) their participation in the monitoring and evaluation of implementation of policy recommendations; 5) the availability of resources to facilitate older caregivers' participation in the development and implementation of HIV and AIDS policies and/or strategic plans; and 6) the informants' opinions on how national policy makers can enable district managers to coordinate activities at a local level in order to support older person households affected by HIV and AIDS. Opinions of the informants and issues which they identified that were prominent in the data, when analysed, are discussed below.

5.4.2 Analyses of data from interviews with government informants

5.4.2.1 *Knowledge and availability of policies and programmes to support older caregivers*

The informants were asked how knowledgeable they were of policies and programmes to support older caregivers affected by HIV and AIDS. Most seemed puzzled that there should be a need for specific policy and programmes in this regard. An informant commented that: "…we work on the basis of guidelines on the HBC (home based care) programme …there are organisations of older persons [that] the department supports…" Hence, such problems according to this informant, were being met sufficiently by programmes such as the HBC and

there was no need for a specific official policy framework to address older caregivers' support needs.

All of the informants indicated that their department has no specific policy to address older caregivers' needs. Nonetheless, a range of opinion on policy intervention to support such needs emerged in the interviews. An informant went to the extent of shifting the responsibility for such intervention to other departments. She commented: "This [older caregivers' vulnerability] is a Social Development [ministry] function. Our department's role is to implement the national strategic plan and policy on HIV and AIDS. I cannot say much on this." Another informant pleaded ignorance on the part of her department of problems faced by older caregivers: "… our department has [only] recently become aware of this problem ….there are no strategies nor policies that have been conceptualised to date to address this issue."

Most informants referred to other mechanisms used or followed by provincial governments to address older persons' needs in general, among which are legislation that provides for the social old age pension and foster care grants, and guidelines for home based care programmes. There were however, the informants explained, no specific mechanisms to support older caregivers. From what could be gleaned in the interviews, the provincial departments seemingly do not see an urgency to address the effects of HIV and AIDS on older carers in a co-ordinated manner; quite simply, the responsibility was shifted to other department(s) or to non-profit organisations.

5.4.2.2 *Role for government departments to support older caregivers*

Most informants acknowledged that there could be a role for their department to provide support to older carers. An informant in KwaZulu-Natal indicated that her department had established and was supporting luncheon clubs where food is provided as well as an environment conducive to socialisation among peers. Her department also provided care to orphaned children by offering caregivers respite in the mornings. Some informants viewed older persons not only as support recipients, but also as a resource in the community and their household. An informant in the Western Cape indicated: "Older persons are a very important support system, and a resource at community level in terms of caregiving to young children… but they need to be capacitated by government about the HIV and AIDS

problem." The informant continued: "Older caregivers can be of use in supporting other older persons who are in the same situation [caring for PLWHA and OVC]."

An informant in the Eastern Cape suggested that her department could play a role by offering life skills development and adult basic education. An informant in the Western Cape identified a role for her department in "upskilling" older caregivers to help them to render better care to their charges. She argued that older carers' role could be expanded to benefit the community as a whole. They could be used as counsellors to infected and affected persons. An informant in the Eastern Cape pointed to an information and education gap in the current support mechanisms provided by government for older persons. He said: "…clearly there are no targeted programmes to meet the support needs of older caregivers. Some provide care to PLWHA and have no knowledge on how to protect themselves against infection. They urgently need information and education." An informant in the Western Cape suggested that the government should find ways to provide financial support to older caregivers, especially those who are destitute (as a consequence of HIV and AIDS).

5.4.2.3 *Putting older caregivers' support needs on policy agendas*

The informants expressed diverse views on how older carers' support needs may best be placed on policy agendas. Most suggested that older carers should mobilise themselves, or form community groups so that their voices may be heard collectively. The informants felt strongly that a solution to older carers' difficulties lay within the carers' power. One informant commented extensively:

You see, within the structure of the Western Cape Province Department of Health there are [sic] the Multi-sectoral Task Team [MSAT]. These structures have representatives from community organisations, the Department of Health, the Department of Social Development, non profit organisations such as Treatment Action Campaign and others. MSAT provide (sic) a forum, maybe an opportunity for grassroots organisations to put their case to government officials. This is a forum where older persons and their organisations can make their voices heard, to channel their concerns up to province and national government. Older persons can also link up with vocal and organised NPOs such as TAC so that their voices can be readily heard. But older persons need to belong to well organised structured organisations to which government can provide support.

An informant in the Eastern Cape echoed this view: "I think they must belong to well structured organisations so that government can interact and exchange views with them on policy issues."

Another view expressed was that the government needed to engage with older carers proactively, as it (the government) is aware of the many challenges facing older persons. Two views in this regard were as follow:

It starts with engaging them [older persons] as stakeholders. Through that, one gets to know what are their needs. However, policy does recognise that they need psychosocial support, need to be cared for, and need financial support. A programme for carers is needed. Poverty reduction programmes must be put in place for people who look after orphaned children and PLWHA. The programmes need to be sustainable, not only provide food parcels.

I think the Department of Social Development needs to raise the issue of older persons who care for PLWHA within government. Coupled with this are issues of poverty, health, abuse many older persons suffer and so on.

An informant in the Western Cape gave an alternative view: "I don't see any particular or specific way that their issues can be put on the agenda. I think when we [government] talk about HIV and AIDS issues it is assumed that everybody is involved. There is a lack of human resources to deal with these specific issues."

Overall, the government informants across the three provinces agreed that older persons are affected by HIV and AIDS and need to be supported. However, there was disagreement on how such support should be provided. Some felt that older persons should "stand up for themselves." Another viewpoint was that the government should raise the issues affecting older persons within government structures.

5.4.2.4 *Older persons' participation in the development of HIV and AIDS policy*

The informants were of the opinion that older persons should be involved in the development of HIV and AIDS policy. However, opinions were diverse on how their involvement should be realised. An informant in the Eastern Cape Province suggested that NPOs working with

older persons should advocate and lobby government to include issues of older persons caring for PLWHA in policy and programme development processes. Other informants felt that existing government initiatives should be used to draw older persons into the processes. An informant suggested that: "They [older persons] can be involved through existing programmes such as LoveLife, where they have projects such as gogoGetters that show the potential that older persons possess to combat the scourge." Another felt that: "... older caregivers must be invited [by government] to stakeholder meetings. We need to identify where older people are, for example, in churches, older persons' club, *stokvels*, old age homes, and engage them, find out what they need. We need to piggyback on what is already there, such as Golden Games, and incorporate HIV/AIDS issues. Their ideas can be accessed this way..."

Two informants were adamant that it rests on older persons themselves, or their representative organisations to find ways for them to become involved. An informant in the Western Cape Province explained:

The way policy develops is through community structures, for example, sex workers, disability groups, trade unions and so on. These structures bring their issues to the table for debate. Older persons need to start their own groups to voice their policy needs or join hands with other well established NPOs so that they can be invited to the policy formulation process. Strangely enough, there are no older person representatives involved in this process [from the province's HIV/AIDS directorate].

Following a similar line of reasoning, an informant in KwaZulu-Natal Province pointed out that: "... they [older persons] or their representatives must attend community forums to put their issues on the policy agenda."

5.4.2.5 *Barriers to older carers' participation in policy development*

Informants expressed contradictory views regarding barriers that inhibit older caregivers' participation in policy formation processes. Some pointed to internal problems in older person organisations, such as poor management structures, and to some NPOs being territorial and unwilling to share information with like minded organisations, as well as to a lack of creativity on their part. (An unwillingness of NPOs to work with each other has been

identified in the literature (International AIDS Alliance, 2002; Jackson, 2002).) Other informants felt that a major barrier was government bureaucracy.
An informant who felt that barriers stem from within the NPO fraternity, which was in disarray, and explained:

One critical issue or barrier is the disorganisation of older persons organisations, especially in rural areas. Maybe in urban areas this is better. Older persons need a platform nationally that organizes them and gathers their concerns. Also what is needed are platforms that function provincially and at district level were most of their day to day challenges happen or can be identified and addressed immediately. At a conference held here in the Eastern Cape in 2005 the issue of districts for a ..... [inaudible] *was hinted at and needs to be taken forward.*

Regarding NPOs being territorial and unwilling to share information, an informant in the Western Cape stated: "... we would like to have more of them and their organisations participating across the province doing work…. but they don't want to go to other areas. ….challenge is to roll out their work. NPOs don't want to go to other areas. The territorial mentality or attitude among organisations is another barrier."

Another informant who viewed a lack of creativity on the part of older person NPOs as a barrier suggested ways to involve older carers, or access their ideas on caregiving. He explained: "...also people are not innovative, they want to do the same old things other NPOs are doing. For example, involving older persons in artistic [sic] forms of knowledge or information." He suggested that NPOs need to explore other ways to disseminate knowledge and information on HIV and AIDS, such as oral history and story telling, at which most older persons are good.

Government "red tape" was perceived to be a major obstacle. An informant in the Western Cape Province stated: "It is not easy for NPOs or individuals to know who to talk to in government. Government departments are huge and bureaucratic. It is easy to submit one's concerns to the wrong person or level or department and this results in people's submissions getting delayed or even lost in the bureaucracy." An informant felt that stigma and ageist attitudes on the part of government officials are barriers to older persons' participation in policy development processes.

5.4.2.6 *Removing the barriers*

Regarding how the barriers to older carers' participation in policy development processes may be removed, some informants felt that it was the government's responsibility to facilitate older caregivers' participation and pointed out that the government needed to find the resources (both human and finance) to facilitate such participation. Others felt it was older persons' responsibility to fight and overcome the barriers themselves. Regarding the view that the government should take responsibility, informants explained as follows:

One thing that needs to happen from a government point of view is that we need to improve inter-departmental capacity and co-operation in addressing older caregiver issues. Government needs to engage NGOs that work with older persons and understand their concerns. Also parliamentarians need to look into this issue when they do consultation in public forums or constituencies.

If one [government] finds things as important or critical you provide finances and human resources to match those priorities, even more so if policy imperatives are such that this sector is important. Your budget needs to be aligned with your objectives with things that are critical and important. We have indicated in our operational plan we will be working with older persons in this financial year as a special sector in relation to HIV/AIDS. We intend to lobby and advocate for a HIV/AIDS dedicated post… personnel or coordinator at district level. We can only provide services properly that way particularly to older persons.... A specific person from the Premier's office has been appointed specifically to look at problems faced by older persons. The Department of Social Development can't do this, it is overstretched.

Regarding older persons taking responsibility to overcome barriers inhibiting their participation in the policy development process, an informant argued that: "Well, essentially [they] need to lobby or advocate hard to make their issues heard. They need to use the media and civil society structures, and build a strong momentum about their cause. Older persons need to be more vocal and visible to be able to overcome the above barriers."

Despite some informants' acknowledgement of a need for the government to involve older persons in the policy development processes as a whole, the informants felt constrained by a lack of resources, and a lack of co-operation and/or policy action and co-ordination between

departments, in what they can achieve. An opposing view abdicated government from taking responsibility to facilitate older carers' involvement and remove barriers to their exclusion.

5.4.2.7 O*lder persons' or their representative bodies' participation in monitoring and evaluation of policy implementation*

Regarding older carers' participation in monitoring and evaluation of policy implementation that affects them, perceptions among the informants were by and large similar. A general view was that older persons' participation need not be treated separately from the participation of other interest groups. A consequence of this attitude had resulted in older persons not being included in monitoring and evaluation processes. Comments in this regard were as follows:

Oh well, the monitoring and evaluation is not specifically focused on older persons roles per se, but looks at the general performance of non government organisations contracted by government …. Chances are that policy developers do not put emphasis on older persons' issues. Maybe more emphasis should be put on older persons challenges by HIV/AIDS policy and programme developers. This area needs serious consideration by government policy makers.

We have not really thought about older persons as such. We do not make a distinction in terms of what age group does what. We have never focused our minds specifically on the role of monitoring and evaluation of HIV/AIDS policy.

One main reason that I can think of is the lack of capacity in the department to concentrate on a specific section of the population. Also one does not want to encourage a linear approach to social problems owing to a lack of resources on the government's side.

This disregard, as would appear above, of the rights of older caregivers or their representative organisations to participate in policy monitoring and evaluation is discriminatory and implicitly indicates discriminatory attitudes on the part of government officials. An argument that a lack of resources prevents the government from addressing older persons' policy needs is negative discrimination, as resources are available to address the needs of other population groups such as children and the youth.

5.4.2.8 *Availability of resources to facilitate older carers' participation in the development and implementation of HIV and AIDS policy*

Most informants indicated that there was a lack of resources to facilitate older persons' participation in the development and implementation of policy and strategies on HIV and AIDS in their departments. Some indicated that resources might be available from the government's side, but seemed to confuse such a need with resources available to support older persons' material needs such as food. One informant felt that it was not her department's responsibility to make resources available for such activities. An informant explained:

Yes, there are resources available, for example, finance from the National Conditional Grant. However, the grant does not look specifically at older persons' issues in relation to HIV/AIDS. Older persons are catered for as part of the broader community and are not targeted as a specific group.

However, the informant contradicted himself by adding*:* "We [government] fund different sectors in the community, for example youth, creative arts, and so on. Therefore, older persons' organisations are also funded in this way."

Two informants on the other hand stated that the government does not make resources available to facilitate the involvement of older persons in policy development and implementation. An informant in the Western Cape Province explained:

Well, yes they [resources] could be made available if we thought about it carefully and strategise accordingly. But it is something we have never considered an issue. The reason is that we don't know much about older persons. Normally, resources are directed where government knows about the problem or issue. For example, homeless children, orphans, HIV/AIDS among the youth and so on.

An informant in the Eastern Cape Province stated:

No, not really. But as far as I know, an organisation called Age-in-Action does engage and mobilise older persons around such issues [resource mobilisation] nationally… I think the availability of resources is a matter that will require lobbying of government ministers, joining of hands by various bodies concerned by older caregivers' issues. Also there is a need

to pool resources together by the various role-players and make an integrated approach in making such resources available.

One informant felt that it was not her department's responsibility to make resources available and shifted the responsibility for such activity to another department, saying: "The Department of Social Development could make them [resources] available, not our department."

Thus, different government officials hold different views and understanding of the availability of resources and making them available to facilitate the involvement of older carers. Their views ranged from being ignorant of older caregivers' needs, to viewing and shifting the role of mobilising resources to other government departments and non profit organisations working with older persons.

5.4.2.9 *Informants' opinions on policy makes' enablement of district managers to co-ordinate activities to support older carers*

Most informants were of the opinion that national government policy makers need to capacitate district personnel through training in the implementation of policy measures. An idea of involving local or district personnel in the policy formation process that would ultimately affect the way they function was deemed unimportant. Most informants perceived policy development to be what Walt (1994:156) has referred to as a "linear" process, where policy formulation is seen as separate from implementation. Thus, policy making is interactive, and formulation and implementation of policy are two elements in a continuous loop (Walt, 1994:156-57). Nevertheless, with the exception of two informants in the Western Cape Province, who understood the importance of district officials' involvement in the entire policy formulation process, which would benefit local role players and communities affected by the scourge explained the process of policy formulation as follows:

…it works in two ways. There is a pathway up, this path facilitates the channelling of community needs to government via structures such as MSAT. One can consider this as a sort of district level body. The information from this level is then channelled to the provincial level which in turn channels the needs to national level. If national agrees that the needs are real or based on facts then policy is formulated at national level, and then this is channelled

back to the province. Provinces then develop programmes to implement the policy that will address the problem. Sometimes, provinces and local government may have powers to develop their own policies. However, a major problem is that provinces and local government do not have their own budgets. Money comes from the national government.

…it's a bottom up approach to policy making process. There needs to be decentralisation of power; more resources need to be put at local or district level. It will be much easier to co-ordinate, disseminate information timeously. More structures, for example local AIDS co-ordinating committees, need a body that will look at older persons' issues. These structures allow engagement with older person and their organisations.

On the other hand a view of district officials as implementing agents appeared to be strongly embedded. An informant explained:

I think a strategy needs to be devised by government such as the inter-ministerial committee [national level], and look at what the policy is saying, whether they are explicit in terms of talking to the issues of older caregivers. If the policy does talk to older caregiver issues, then they must check whether the policy provisions are implemented at district level. If they are not, then government will have to capacitate district officials to implement the policy.

Another informant held the following view: "Officials at local level will have to be trained on how to work together with older persons and their representative organisations at district level. Facilitating forums between district management and older persons' NPOs must be created to perform this work." Yet another informant felt the only way to address the problem was to strengthen what is already in place at district level. However, forgetting the limited resources that officials at district level must struggle with, he said: "It is by strengthening the HIV/AIDS multi-sectoral forums operating at community level [that will serve as the voice of older carers on their policy needs]."

The informants therefore held opposing opinions, which may have been a function of their experience with policy formulation. Most policies that provincial officials deal with are formulated at a national level, or adapted from national policies. Hence, what was evident was a failure to appreciate the importance of involving district officials in the formulation of policy that would enable district officials to co-ordinate the activities of different role players.

5.4.3 Analysis of data from interviews with NPO managers

Data gathered from the interviews with three managers of non-profit organisations in three provinces are analysed below. All of these informants were female and middle-aged. One had trained as an occupational therapist, another was a retired professional nurse and a third was a retired teacher. Their years in practice ranged from 10 to 20. They had worked in public hospitals, public schools and/or non-profit organisations. The analysis is organised in four categories, which correspond broadly with the open-ended research questions put to them in the interviews. The four categories are: 1) Awareness of the national HIV/AIDS strategic plan; 2) accessibility of the HIV/AIDS strategic plan; 3) mechanisms to involve NPOs in monitoring and evaluation of policy implementation; and 4) facilitation of older person NPOs' involvement in HIV/AIDS strategic development.

5.4.3.1 *Awareness of the national HIV/AIDS strategic plan*

All three informants indicated that they were aware of the national HIV/AIDS strategic plan. However, only one stated that her organisation had a copy of the plan in its possession – somewhere in the office, but she was not able to find it immediately. Another informant replied: ''… we just heard the information from a local community meeting that a document like this exists." Hence, in all, the informants may not have been fully cognisant of the contents of the plan.

When the informant who stated that her organisation has a copy of the strategic plan was asked how she had obtained it, she replied: "I think I picked it somewhere. I picked it up at a launch of the strategic plan. It was a government called meeting, and then I picked it up."

It may be accepted that accessibility of government documents to lay persons is complicated, owing to bureaucracy, and ignorance of the existence of the documents and how to contact the relevant government department to obtain a document. When the three informants were asked whether their organisation had received an invitation to be part of the strategic plan formulation process, all replied negatively. An informant replied irately: "No, no, no, our organisation was never involved in any way in the development of this strategic plan you are talking about." The other two informants said they had not been invited, but had heard that meetings on developing the document were being held in their area.

5.4.3.2 *Mechanisms to involve NPOs in monitoring and evaluation of implementation of the strategic plan*

Monitoring and evaluation are an essential oversight function in policy implementation, and provide policy makers and managers with direct feedback on the implementation of a particular policy (Walt, 1994). The informants were asked whether monitoring and evaluation of the implementation of the HIV/AIDS strategic plan had had adequate mechanisms in place to involve NPOs in the processes of the national strategic plan. The informant who had read the document replied: "No, not at …well I can't say I noticed anything said on older persons, so I did not bother reading further about the plan… it did not address my area of interest, you see."

When asked about barriers to, or reasons for the non-participation of older persons in the development and implementation of the plan, an informant replied: "Ja, it all has to do with communication from the government's side which is problematic. There is poor communication from government offices to role players at community level." Another informant complained about the government's attitude towards older persons' difficulties compared to other sections of the population and stated: "[The] working relationship between government and older persons' organisations is not strong. Government does not regard older persons' issues very seriously compared to children's problems and the youth."

Reasoning similarly, an informant suggested: "I think the problem is more to do with not paying too much attention to problems affecting older persons and their organisations by government and business. For example, when we apply for grants for older persons looking after orphans we always get letters regretting or refusals to issue grants."

When asked how a relative lack of attention to older persons' needs could be remedied, two informants were unsure but offered reasons why the government possibly responds in the way it does: "Mh-h-mh, I would not know, maybe because government thinks older persons are no longer going to contribute in society anymore as compared to children and the youth. That is why."

Another said: "I… I… I'm not quite sure, because the problem is mainly with the offices in Home Affairs. For example, they will ask for all sorts of documents such as birth certificates,

the death certificate of the child's parent. When one applies for these [documents] they take a long time to be processed. Sometimes when they are successful, the person has already died or something like that."

Preferring not to sound judgemental about the government, an informant said: "Well, people in government responsible for policy development are interested in involving a diverse group of people including older persons, [but] then they need to invite representatives of the groups to participate in the process of policy development."

5.4.3.3 *Facilitation of older person NPOs' involvement in HIV and AIDS policy development*

When the informants were asked how the district or local government could facilitate the involvement of older persons or their organisations in future HIV and AIDS policy development to benefit older caregivers, all three agreed that the government must engage NPOs representing older caregivers directly, and suggested different mechanisms on how to achieve this objective. An informant commented extensively:

Well, number one, there needs to be somebody from the local office who is aware of policy planning who knows what is going on in provincial office and national office. That person needs to make it their business to invite and engage role players at district level in the plan and discussion of policy development. And then to be responsible enough to take matters to the next level. There is clearly no one at district office who knows what is going on at the upper levels as far as policy is concerned. Clearly, there is no one who plays that role at the moment. Officials at local/district level are busy with organising the day to day administrative duties such as organising social grants. No one is charged with policy development and or implementation. The organisation of role players to participate in these processes is very bad.

Another informant complained bitterly about the exclusion of older caregiver NPOs and said:

I, I, I think the offices [home affairs, social workers and others] need to be closer to the communities. We are isolated, we are not visited by government officials. We are not taken seriously as compared to other NPOs such as those working with orphans and street children …For example, we do not have money for transport to transport older persons to far away

offices in the city. Government must involve us directly in these activities. We have experience from working with poor and suffering people for more than five years …it is very difficult to receive funds from government, especially for activities to older persons affected by HIV/AIDS…

The third informant added: "Meeting with older persons' organisations such as ours must be organised by government social workers, where we can discuss together on how best we can share ideas on how to involve older persons and their organisations in the process of policy making."

Clearly, older person organisations are keen to be involved at a district level in policy formulation processes, as evidenced in the complaints that were levelled against the government's exclusion of older caregiver NPOs in these processes. However, the informants were not only critical of the government's approach or stance, but made suggestion as to how the situation might be corrected, to benefit their organisation's members. Suggestions made included the government's consultation of older persons' representative NPOs, and the appointment of dedicated district policy to facilitate deliberation between community organisations and government personnel at district level.

5.4.4 Discussion

In essence, both the government informants and the NPO informants agreed that no policies are in place to support older caregivers. Both groups identified a need for older persons or their representative organisations to be involved in policy development and implementation processes. Both proposed mechanisms through which these objectives could be realised. Although the government key informants were sympathetic to the inclusion of older carers in related policy processes, they were of the opinion that it is up to older persons or their representative organisations to organise themselves as a group and to participate in policy formulation and implementation processes. Government informants suggested structures such as the MSAT (Multi-Sectoral Task Team) as appropriate vehicles through which older persons could make their voices heard in policy development. However, these structures are largely unfamiliar to older persons' representative organisations, which suggests that they and their activities are poorly marketed by the government at a district or local level.

The NPO informants were less forthcoming on the matter of older persons' participation, mainly owing to a lack of information and their own low level of participation in policy formulation processes. They indicated that they were unimpressed with the way in which the government developed policy. All of these informants complained about the government's lack of consultation with organisations such as theirs. As a consequence, two of the three NPO informants were ignorant of the national HIV and AIDS strategy plan. The informant who knew about it was not well informed about its provisions. These informants felt that the government worked in a complex and bureaucratic manner, which made it difficult for older persons to participate in processes, or to submit their concerns and needs to the relevant government structure(s). Nonetheless, despite feeling excluded in policy development processes, the informants emphasised that older persons' representative organisations were willing to participate in these processes and that such participation would benefit their members.

Both groups of informants agreed that a structure or an individual was needed at the district level to serve as a policy co-ordinator, and as a link with higher levels of government and affected communities. This would facilitate the participation of older persons, their representative organisations, local government personnel and older caregivers themselves in deliberations, and ensure that their perceptions, experiences and needs were taken into account. Such an approach would fulfil a central principle of the UN' Principles for Older People, which encourages older people's full participation in all matters affecting their lives (UN, 1991).

PART 4: TRIANGULATION OF THE DATA

5.5 TRIANGULATION OF THE DATA FROM THE THREE SOURCES

Data collected from the three sources – a survey (Part 1), an in-depth interviewing study (case studies)(Part 2) and interviews with key informants (Part 3) – were analysed and the results shown and discussed above. These results are now triangulated to provide a comprehensive picture and understanding of the situation of affected older persons – from both a client perspective and a provider perspective. Triangulation combines the results of analyses of data gathered from multiple sources, possibly using multiple methods. In the present study, both the quantitative and qualitative research methods were used to gather data. Triangulation of

the results of the analyses will indicate the magnitude of the problem, from the perceptions of various role players and stakeholders, and what solutions in the form of policy and intervention may be desirable and feasible.

As indicated in Chapter 4, triangulation is used as a tool 1) to confirm, cross validate and corroborate results obtained from the use of one analytical technique with those obtained from the use of other analytical techniques (Green, Caracelli & Graham, 1989; Poundstone et al., 2004), and 2) to strengthen overall findings. In the present case, information obtained from the case studies was corroborated with survey data, in specific domains, by comparing the two sets of data and identifying areas of concurrence or divergence in the data. In general, the information obtained in the case studies corroborated that from the survey, and *vice versa*. In addition, the case studies yielded information, not solicited nor recorded in the survey, an analysis of which served to enrich an understanding of the carers' situations.

The strength of the survey data lies in its description of the magnitude of the difficulties that older carers in the three provinces, in both urban and non-urban settings, face in day-to-day caregiving. The survey demonstrated a wide range of activities in which the carers engage in rendering care to PLWHA and OVC. The analysed survey data also yielded measures of the respondents' health status and, objectively and subjectively, the extent to which they need to be supported in order to reduce their caregiving burden. However, on their own, the survey data were unable to provide a full understanding of the caregivers' experience of caregiving, nor how they cope with the challenges of caregiving; such understanding, then, was achieved in the analysis of the case study data. That said, the case studies were only conducted in a single province (the Western Cape), and generalisation of these findings to settings in other provinces may be limited.

The case studies elaborated the perceived greatest difficulties the carers' experience in caregiving, because of their health conditions. Rather than mere self-reports of the presence of a health condition, the in-depth study findings indicated the nature of the illnesses, complications and new conditions that developed as a result of caregiving – such as sleeplessness, crying and a worsening of their diabetes. The carers were able to verbalise moreover reasons why they are unable to engage in paid employment, which they explained was because of their caregiving responsibilities. In addition, they were able to explain how they coped with caregiving under these circumstances. Some, for example, engaged in petty

trading, but for which they needed to borrow money from money lenders to purchase goods to sell, with lenders charging a high interest rate.

The carers were also able to express themselves on matters relating to HIV and AIDS. The majority, for instance, were knowledgeable about the disease, but some believed that infection with the virus is punishment from God – which finding concurred with the survey data. Finally, the case studies enabled carers to articulate their experience of AIDS related stigma. For some, the fear of gossip, discrimination and violence against their families by some community members was uppermost in their not disclosing the status of an infected person in their household.

A contradictory finding in the analysis of the in-depth study data was that some carers feared "harsh treatment" from certain health professionals at public health service points. By contrast, the survey data analysis indicated a notably high level of satisfaction with services and treatment at these facilities. The in-depth interviews therefore afforded the respondents an opportunity to verbalise some of their experiences more thoughtfully and frankly than by merely responding to fixed-response items in the survey questionnaire.

Data obtained from the government key informants suggest that a major gap exists between the challenges and hardships that caregivers face and the level of understanding of the government of their challenges and hardships. Consequently, the government's responses to older carers' support needs have been inadequate or non-existent. Indeed, the government key informants appeared more concerned about denying that it was their department's responsibility to involve older carers and/or older persons' organisations in policy processes that affect carers. Rather, they blamed bureaucracy for a lack of consultation and inclusion of these stakeholders, and tended to shift the responsibility to older caregivers and NPOs. By and large, the government informants appeared to be unaware of how desperate the situation and plight of older carers are. By implication, they appeared to expect that older carers, triple burdened by caregiving, poverty and their poor health, should themselves take responsibility for making their voices heard. These informants overlooked the carers' vulnerability on several levels: one being the carers' low level of education and inability to articulate their needs and demands, and another being their lack of knowledge on how government structures work and how to access them.

Ageist attitudes on the part of some of the key informants were seemingly an underlying problem in their lack of understanding, sympathy and response. Some advanced an argument that the government lacks the capacity and resources needed to attend to the needs of a specific section of the population, i.e. older persons; yet the government promotes and supports programmes targeted at the youth, the homeless and orphaned children. Ageist attitudes of some government informants were highlighted by an NPO informant, who alluded to the perception of government that older persons are a spent force and no longer contribute to society. A lack of consultation with older persons' representative structures is further evidence of ageism and age based discrimination against older persons. Again, a lack of support from the government indicated by the survey respondents (in Part 1) is confirmed by a lack of knowledge about caregivers' needs acknowledged by some government key informants (in Part 3). Nonetheless, a positive sign is that some government informants showed a willingness to involve and work with older persons' structures as a way to address older carers' needs.

Despite not being consulted on issues relating to HIV and AIDS intervention, as pointed out by the NPO informants, older caregiver NPOs steadfastly work and support older caregivers, as evidenced in findings in the case studies (Part 2). The majority of these survey respondents reported that their knowledge and information about the disease was acquired through an NPO. In addition, some reported they receive material assistance, acquire income generation skills and enjoy broad support from an NPO on an ongoing basis. The anomaly of government not working with NPOs, which have first-hand information on and direct contact with older caregivers, cuts across all three provinces. The government's lack of consultation with NPOs in effect disempowers the organisations, and these informants expressed frustration and a sense of helplessness (Part 3). Similar frustration with the government's functioning was expressed by respondents in the case studies, who referred to the inordinate time that government bureaucracy takes to process and approve an application for a grant.

The above interpretations of the triangulated data aside. Some minor difficulties encountered in interpreting this data warrant mention and indication of how they were overcome. The first difficulty was combining and integrating three data sets of hugely different proportions: The survey data (n = 305), the case study data (n = 10) and the key informant interview data (n = 9). Moreover, the case studies were conducted in only a single province. In addition, the survey data comprised mainly responses to structured items, whereas the data of the other two studies were responses to open-ended items. The combination, comparison and potential

correlation of some data in three data sets could have been inherently problematic. However, this problem and other problems were solved as follows:

A first problem was that of the researcher's subjectivity and consequent bias in the interpretation. Such bias could have entered through his disciplinary orientation and cultural experience, and his knowledge of the study context. In interpreting the data, the researcher had to guard moreover against slipping from facts and data to inferences – some inferences possibly unsupported by the data (Levinson, 1994: 43). I therefore endeavoured to cite the facts in respective data sets from which inferences were made. Similarly, I endeavoured to genuinely represent the respondents' views and circumstances, and to not select issues of concern or interest to him. Additional steps taken to ensure that interpretation remained objective included i) engaging in self-reflection (Burns & Grove, 2001), in order to be aware of potential biases and avoid them, and ii) presenting the triangulated data and his interpretations to his supervisors, as mentors, for scrutiny and affirmation.

A related problem was how the researcher should provide an accurate account of the information and interpretation. In quantitative research, verification of the accuracy of such reporting may be conducted through "debriefing" between the researcher and the study participants (Berg, 2001). In the present study he used a triangulation strategy *de facto* to verify the accuracy of his reporting and interpretation. The strategy helped him moreover to identify instances of convergence and/or divergence in the data sets.

Finally, the researcher had conducted the ten case studies and documented the participants' experience in the field himself, which provided him with a firsthand and in-depth understanding of the phenomenon under study; he was able therefore to communicate a detailed and credible account of the study settings and the carers' situations. This information and interpretation could be effectively employed in the triangulation of the case study data set with the survey data set. However, more problematic was the triangulation of the key informant data with the data and findings of the other two data sets, but largely for reason of the informants' relative lack of understanding of the carers' situations, and the paucity of government responses and a strategy.

In summary, the evidence presented from the analyses of the data from the three sources

validates the need for policy development to support affected older carers, in order to reduce the effects of the epidemic and to ameliorate the care burden of the epidemic on their well-being. A policy framework, informed by the evidence of the older carers' situations, and gaps in responses, as identified in the multiple datasets, is developed and proposed in Chapter 6. The policy framework will aim to guide stakeholders towards the development of strategies and responses that ensure the welfare and health of present and future cohorts of older caregivers are sustained, through expanded provision of formal support and support of the activities of non-formal service agencies.

5.5.1 Theoretical view of the results

The study results presented and discussed in this chapter, and triangulated in the sub-section above are predicted by the theoretical framework used in the dissertation. From a feminist theoretical perspective, and taking into account that older women constitute the majority of older caregivers to PLWHA and OVC, who thus carry this burden, they were found to be markedly disadvantaged and marginalised when it comes to support and counselling. The low level of recognition of the onerous task of caregiving in this case may be attributed partly to a patriarchal societal attitude that caregiving is a "natural" task for women – who are viewed as nurturers, not providers (only men are providers). What is significant moreover is that other than older women constituting the majority of informal carers, the large number of (non-formal) NPOs working against HIV and AIDS are primarily co-ordinated and managed by women as well. However, in the case of older women, who lack power through a low education level, few financial resources, and few political connections, as well as their low status in a patriarchal society, they are at risk of becoming isolated and their limited resources being over stretched. It is evident from the analysis of the data in this dissertation that the HIV and AIDS epidemic presents severe socio-economic and psycho-social challenges for the carers, female caregivers in particular, which then calls for gender and age specific interventions. An understanding of the partriarchal society in which these women live and care is thus similarly important in the design and implementation of appropriate interventions (Arhihenbuwa, 2003).

In conjunction with a feminist perspective on caregiving, a social exchange theoretical perspective has provided for an understanding of the underlying reasons for and dynamics of caregiving by older persons. Although social exchange theory argues a case for reciprocity

within dyads (of caregivers and care recipients) and within social networks in which care is rendered, this reciprocity may be immediate or delayed for the future, owing to the inability of one actor to reciprocate because of a disadvantaged position. In the case of the present study, OVC are not in a position to reciprocate what the caregiver provides immediately, but the caregiver may anticipate reciprocal care and support when she (or he) is old and possibly frail and in need of care and support. Hence, social exchange theory is unable to predict exchange reciprocity in this case

Following on the perspectives employed for viewing and making sense of the data and the findings, it is evident that planned interventions should be age and gender sensitive. In addition, interventions should link with caregivers' social networks and support systems, such as NPOs, churches, clubs and burial societies to which they belong, or are operated in their communities, to restore reciprocity.

CHAPTER SIX: A POLICY FRAMEWORK TO SUPPORT OLDER CAREGIVERS AT THE DISTRICT LEVEL

6.1 INTRODUCTION

It is well known that government policy makers are frequently unresponsive to empirical evidence on situations that should be remedied, sometimes through a lack of political willingness, or because of other priorities in the allocation of scarce resources**.** Feldman et al. (2001: 312) have suggested**,** tongue in cheek, that, "Researchers are from Mars, policy makers are from Venus." Nonetheless, researchers should be undeterred by policy lassitude, and proceed to produce and provide evidence-based information on the experiences of affected groups, with an intention to inform government policy and action. The uptake of such pertinent evidence by policy makers and its translation into policy and practice, however, may be poor – owing to a need to respond to the competing demands of multiple interest groups. Richardson and Jordan (1982) have referred to an "over-crowdedness of [the] policy environment," which makes decision making difficult.

Information gained from the empirical study as well as a review of the relevant literature and policies presented in this dissertation describe the magnitude of the problem of the effects of HIV and AIDS on older persons and their support needs, where they are caregivers to affected family members. The information includes characteristics of the affected group, and provides an understanding of the obstacles that carers in both urban areas and non-urban areas face. The findings indicate indirectly how various affected and vulnerable sub-populations (grandchildren, adults and older persons) might benefit at a household level from relevant policy and action aimed at mitigation of the effects of the epidemic on older caregivers.

Indeed, intervention aimed at benefiting all affected members of a household is indicated. Although older persons carry the greatest responsibility of caregiving in households where adults are ill or have died as a result of AIDS, in some cases care is being provided by orphans who are in truth too young for this responsibility. The two sets of caregivers face similar and different challenges. Orphan caregivers face several constraints, especially if their parents died as a result of AIDS (Ntozi et al., 1999). They and their siblings may face hunger on a regular basis; other vulnerabilities include facing an uncertain future regarding their

custody and sometimes having to drop out of school to take care of siblings. Some are dispossessed of their parents' property (HSRC, 2002; UNICEF, 2004). The caregivers' roles are similar however in that both are providing care at a time that is out of synchrony with their age: older persons may have expected to have "retired" from caregiving responsibilities; orphans are too young and lack experience to care for others on their own. Another similarity is that both are vulnerable: orphan carers lack the protection of their parents; older carers may suffer ill-health, and may be without a partner and their adult children may have moved away. Both sets of carers are at risk moreover because of the impact of poverty on their lives. What differentiates the sets however is that older carers no longer have the stamina to care and may be burdened additionally by compromised health.

In this chapter, pertinent evidence gained from the empirical study is presented to support the development of a framework to inform new policy formation and programme design and implementation aimed at supporting older caregivers at the district level. In addition, gaps identified in chapter 3 with respect to government instruments' inability to address some needs of older persons, such as the provision of dedicated health services at district level, are focused upon. The chapter is organised in six subsections: 1) A brief overview of the relevant literature and extant policy, as reviewed in chapters 2 and 3, and an elaboration of a rationale for a policy framework. 2) An interpretation of the study findings within a policy and institutional context. 3) An interpretation of evidence from the case studies and key informant interviews for their policy implications. 4) An outline of a policy framework. 5) A plan of action for the formulation, adoption and implementation of new policy and programmes to support older carers at the district level. 6) An identification of additional information needed through future research in this area.

6.2 LITERATURE AND POLICY REVIEW OUTCOMES, AND A NEED FOR A POLICY FRAMEWORK

The review of the literature on HIV and AIDS and older carers in Chapter 2 identified main issues relating to caregiving and the carers' situations in developing country contexts, specifically within Southern Africa. Older carers not only suffer chronic poverty, but experience unresponsive and inadequate health care services, difficulties in caring for young children, unsatisfactory living arrangements, specific challenges in rural settings, disrespect for their human rights and stigma as well. In addition, they are systematically marginalised in

HIV and AIDS interventions. Many report experience of negative and discriminatory attitudes from community members and health service providers (see WHO, 2002a; Knodel, 2006). The majority fear for the future of their children (PLWHA) and grandchildren, should they (the carer) die first.

A contemporary concern in developing countries is the increasing number of older persons who are themselves at risk of infection with the HI virus, either as a consequence of caregiving or poor reproductive health behaviour and care (CSO, 2008). Moreover, older persons are typically assumed to be sexually inactive, and less likely than young people to be at risk of contracting the virus; as a result, infected older carers are less likely to present to a voluntary counseling and testing (VCT) centre, or be encouraged to do so, for diagnosis and treatment. Nonetheless, irrespective of being affected or infected, older persons play valuable roles in their homes and communities as frontline carers, peer educators and counsellors (HelpAge International, 2005c). Hence, support interventions to mitigate the effects of HIV and AIDS on individuals and communities need to take into account the interdependence of affected groups: PLWHA, OVC and older caregivers alike. Of crucial importance is the development of a comprehensive policy framework aimed at the support of older carers – in their caregiving responsibilities, and to enhance their own health and well-being. Of equal importance is that programmes designed and implemented to support older carers ensure that responses to the epidemic occur in a co-ordinated manner, and are inclusive of all stakeholders.

A need for a policy framework to support older caregivers is proposed based on the review of relevant policies in chapter 3. The review found that relevant policies and their implementation are largely sectoral; responsibility for policy formulation is vertical and compartmentalised; and older persons and their representative organisations are hardly mentioned or involved in policy development processes.

The implementation of the South African government's strategic plan on HIV and AIDS is by and large left to NPOs. Government intervention such as prevention campaigns and support focuses on the youth and orphaned children, and overlooks, the effects of the epidemic on older persons. A mindshift and policy reformulation are therefore indicated. A major goal of such a shift in focus, should be the promotion of a strong district level strategy and the

capacitation of district level personnel, to be inclusive of older persons' needs as identified in this dissertation and the empirical study.

6.3 SURVEY OUTCOME AND THE IMPLICATIONS FOR POLICY

The survey outcome provides empirical information to inform responses to the diverse support needs of the carers. Key outcomes of the survey in this regard are as follows:

1) The financial situation of the carers and their household is obviously dire. Apart from social pension income (in the majority of cases) and income from child support grants (in a few cases), older carers receive little or no additional financial support. Although formal social safety nets are available to most carers, the resources they provide are insufficient, and are simply not designed to support caregivers faced with the complex and costly demands of caregiving. Older carers need dedicated social protection in the form of a specific PLWHA caregiving grant (see e.g. HelpAge International, 2004b) - separate from the existing generic caregiving grant, to help them to meet caregiving related expenses, for which no provision is made at present.

2) The majority of caregivers have particular vulnerabilities as a consequence of historical disadvantage and inequity, their low socio-economic status, their relative lack of access to resources, little formal support and the burden of care. The low levels of education of the carers, for example, limit their ability to access and use resources provided under the country's constitution. Hence, consideration should be given to improving older persons' access to adult basic education outreach programmes, especially in rural settings.

3) The carers in the survey reported poor health generally. The burden of caregiving was found to aggravate existing health conditions and to contribute to new conditions. Programmes to protect and improve carers' own health could help additionally to enhance and safeguard the health and well-being of dependent household members, such as grandchildren.

4) The majority of the carers were knowledgeable about AIDS: its causation, and who is at risk of contracting the disease and how. By implication not only may older carers be

amenable to participation in education and training programmes aimed at combating the epidemic, but they also constitute a resource that should be supported and included in policy development and implementation processes (see UN, 2004a).

5) Non-profit organisations play a key role in providing support to older carers and their households, specifically through training on HIV and AIDS, advice given on day-to-day caregiving, skills development and financial support. NPOs should therefore be included in an integrated and multisectoral approach to improve the situation of older carers.

6) Disclosure of the HIV and AIDS status of an individual within a household and stigma relating thereto are clearly difficulties with which older carers must cope. Stigmatisation of the disease persists in the carers' communities, and negative attitudes towards affected households and family members were found to be a serious obstacle to carers' ability to access help resources. Nevertheless, family members were found to be a strong source of support to a PLWHA, and a policy framework should therefore include recognition of families as a resource in efforts to reduce stigma (see UN, 2004a).

6.4 EVIDENCE AND POLICY IMPLICATIONS FROM THE CASE STUDIES AND KEY INFORMANT INTERVIEWS

Evidence from the case studies not only corroborated the survey outcomes, but provided additional information on the physical and mental health and effects of a loss of earning capacity of the caregivers. The multiple strains on the caregivers diminish their capacity to cope and to nurture grandchildren in their care. Although most were knowledgeable about HIV and AIDS, some carers nevertheless displayed confused and fatalistic beliefs about the disease, which suggests that more needs to be done to educate and correct misconceptions among a section of this population. Desperate for a cure for the PLWHA, and through confusion, some carers seek help from traditional healers and incur enormous expenses in the process. Some carers fear abusive treatment from health professionals at public health care facilities, which calls for mechanisms to be put in place to inform and educate health providers on the consequences of intimidating older carers, and PLWHA and vulnerable orphaned children whom the carers take to public facilities for health care.

The case studies also highlighted the coping mechanisms of older carers in dealing with their dire household financial situation. Some borrow money from money lenders who charge high interest rates and in some cases illegally confiscate a borrower's identity documents as surety against the loan. The range of coping strategies of the carers indicates their capabilities but also that they need formal support from the government.

The government key informants, by and large, understood a need for older persons, or at least their representative organisations to be involved in policy development processes, even though they tended to shift the responsibility for doing so elsewhere. The NPO informants criticised the top-down approach in policy development as non-consultative and exclusionary, and lacking in transparency. They highlighted the complex and bureaucratic manner in which the government works, which creates barriers to the participation of interested parties. Nevertheless, although the NPO informants felt alienated from policy development processes, they were keen to engage in policy development and felt that such participation would benefit their members. The UN General Assembly Special Session on HIV/AIDS (UN, 2001) has called upon governments to develop or strengthen strategies, policies and programmes which recognise the importance of the family in reducing vulnerability and coping with the disease. However, without the involvement of older persons or their representative organisations in policy mechanisms to address their problems, such provisions will remain empty words. Relevance of the evidence from the key informant interviews for the development of a policy framework is considered further below.

6.5 A POLICY FRAMEWORK TO SUPPORT OLDER CARERS

The policy framework proposed here is a response to that call, and is intended for use by government policy developers, non-profit organisations and other role players in this field. In line with the UN policy framework on HIV and AIDS and family well-being in Southern African countries developed earlier (UN, 2004a), the framework developed in this dissertation could serve as a mechanism for role players to use in order to review, analyse and reformulate existing policies and programmes. Support for older carers can contribute to the cohesion and stability of affected families and households and avoid their dissolution. Hence, the framework could be used to analyse whether policies and programmes address older carers' needs in a manner that supports caregiving activities, and enables the carers to provide

shelter, food, clothes, health care and education for affected household members, and sustains their own physical and mental health and well-being.

In addition, the framework could be used to draw input and comment from a broad range of stakeholders as a consultative document. Consultation may be carried out by NPOs representing older persons, who could use the framework to lobby the government. The older person representative NPOs could present the framework to the government at a provincial level, and to other stakeholders for collective action by all the role players to support older carers. Employment of the framework for these purposes could serve moreover to support all vulnerable older persons and their families, and not only those affected directly by the disease. Indeed, if new policies and programmes target only older persons affected by HIV and AIDS, problems such as stigma and discrimination faced by older carers' family and household could be exacerbated, since they and their family members might be isolated and harassed by community members owing to perceived government preferential treatment. Responses to the effects of the epidemic must thus target affected persons in all age groups and affected families in an integrated and comprehensive way (see UN, 2004a).

A policy framework based on the evidence presented in this dissertation is outlined below (see Figure 6.1). The framework has nine key desired outcomes, each with a basis for action, policy recommendations and potential indicators. The indicators suggested to measure government and civil society responses are tentative, and are intended for wide discussion and reformulation with role players at the district level. Proposals shown in Figure 6.1 are elaborated below.

The nine desired outcomes shown in the framework (Figure 6.1), together with the bases for action, policy recommendations and potential indicators are discussed separately for each outcome. The framework is directed at national, provincial and district levels, to be elaborated in a proposed action plan later in this chapter.

Figure 6.1: Policy framework for the support of older carers at district level

	Desired outcome	Basis for action	Policy recommendations	Potential indicator(s)
1	Strengthened capacity of older carers to care for infected and affected persons, and to protect themselves against HIV infection	Carers need access to information and resources to enable and equip them to care for PLWHA and OVC, and to protect themselves from infection	• Review (and reform, where appropriate) current policy and programme intervention on HIV and AIDS, to ensure older carers' inclusion and make provision to address their specific needs; • Provide carers with information, counselling support and life skills training to empower them and enhance their caregiving;	• Number of age appropriate information materials developed and distributed to educate older persons on HIV and AIDS; • Number of district health service points with dedicated staff to counsel and support older persons on HIV and AIDS;
2	Improved access for caregivers to essential services, including health care, water and sanitation.	Older carers may experience difficulty in accessing health service points and lack modern amenities in their dwelling.	• Ensure that basic health and nutrition services (e.g. vitamin fortified mealie meal) are available to older carers; • Assess older carers' dwelling infrastructure, and access to safe water and sanitation to facilitate caregiving; • Strengthen district planning and programmes by involving older persons or their representative organisations in the process.	• Number of older person headed household benefiting from government nutrition support programmes within a district especially rural communities; • Proportion of older persons' households with piped water and a flush toilet; • Number of district management teams with older persons or their representative organisation, per district.
3	Involvement of older carers or their NPOs in policy development (e.g. social grants policy)	The roles and contributions of older carers (e.g. caring and nurturing) must be recognised and supported by government, to enhance the capacity and caregiving carers	• Review and reformulate policy and programmes to ensure inclusivity and non-discrimination against older carers; • Encourage affected households to access social grants for which household members may be eligible; • Ensure that government departmental budgets provide for programmes to support older carers' households;	• Percent older persons or their representative NPOs participating in policy formulation processes; • Number of AIDS-disabled PLWHA receiving a disability grant per year; • Number of government departments budgeting for older persons' needs;

Cont./

Figure 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
			• Ensure that policies and programmes to support PLWHA promote family cohesion and solidarity, and encourage and enable orphaned children to remain with family; • Ensure that government departmental policies mainstream older persons' needs in general.	• Percent older persons' households receiving full municipal services per year.
4	Co-ordination of activities to support older carers at the district level	The numbers of poor and older persons with a commensurate demand for services are increasing	• Build the capacity of district level officials to become actively involved in policy development aimed at addressing the epidemic at a community level; • Ensure that district services reach vulnerable households; • Establish co-ordinating mechanisms at district level to ensure the exchange of information and collaborative efforts; • Strengthen district efforts to support sustainable and accountable responses to the epidemic; • Build strong working partnerships between district management and NPOs working with older carers.	• Proportion of district managers trained in policy development and implementation; • Number of districts with a fully functioning co-ordinating body at the end of each year; • Number of districts with a working partnership between district management and NPOs representing older persons per year.
5	Avoidance of ageism, stigma and discrimination	Concerted efforts are needed to address prejudice against older persons, and problems of HIV/AIDS stigma and discrimination against their households, through awareness campaigns that involve community leaders and convey key messages to different sections of the community.	• Encourage community leaders to talk openly about HIV and AIDS and their impact on older persons; • Encourage the identification of affected older person households and help to mobilise community responses;	• Number of workshops, public meetings and campaigns organised by community leaders to address issues of HIV/AIDS stigma and discrimination per year; • Proportion of affected older persons household identified and assisted through community efforts

Cont./

Fig 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
			• Destigmatise HIV and AIDS within families by targeting information campaigns and providing counselling to all family members.	
6	Engagement and dialogue with traditional healers on HIV and AIDS and older carers	Traditional healers live and work in the communities that are poor and most affected by HIV and AIDS	• Involve traditional healers in the mainstream public health approach in managing the epidemic; • Capacitate traditional healers through dialogue and educate them on the causation and spread of the disease; • Encourage traditional healers to help to counter myths, and promote responsible attitudes and behaviour towards older people and the epidemic.	• Number of traditional healers engaged in dialogue and educated on HIV and AIDS by government at district level; • Number of traditional healers educated in VCT counselling per district per year; • Number of HIV and AIDS clients referred by traditional healers to a district health service point.
7	Identification of older carers' need for adequate shelter and assistance with home improvement	Affected households accommodate a number of vulnerable family members. Physical space and the home environment are often inadequate to accommodate all household members	• Expedite delivery of affordable housing to indigent and affected families. Improve older carers' access to credit and housing loans; • Assist affected households with home improvement (room extensions, indoor water and sanitation, etc.)	• Percent of affordable, sufficiently spacious houses occupied by older caregivers per district per year; • Percent of older persons accessing micro credit and/or credit and housing loans per year.

Cont./

Figure 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
8	Promotion of age-friendly district health service points.	Older carers have multiple chronic health problems, and the strain of caregiving engender additional health problems	• Establish age-friendly health service points at the district level; • Train health providers at the district level on the relationship of age related health conditions and HIV and AIDS; • Improve referral systems for older clients, to enable them to conserve resources.	• Number of health service points with age friendly environments; • Proportion of health service points with effective referral and appointment systems for older persons per district; • Number of clinics with dedicated services for older persons per district health facility per month.
9	Raised awareness and increase advocacy for community mobilisation to create supportive environments for older carers.	The impact of HIV and AIDS on older carers, their families and communities cannot be addressed by any single sector. A multisectoral (i.e. public, private, traditional and/or community) approach is required	• Link HIV and AIDS prevention activities and care and support for PLWHA with support for older carers; • Encourage and support local initiatives that promote community and family solidarity, to withstand the direct and indirect impact of the disease on households; • Disseminate successful experiences and lessons learned in raising awareness on the plight of older carers. • Use of mass media (e.g. TV, radio, pamphlets and billboards) and interpersonal communications strategies which are culture based and targeted to the intended audience.	• Number of joint public gatherings and awareness campaigns designed to highlight the plight of older carers per year; • Number of materials produced and distributed on successful best practices to help raise awareness about older persons' plight per district. • Number of TV and radio programmes providing information on HIV and AIDS directed at and inclusive of older persons • Number of billboards and educational materials displayed in public spaces.

6.5.1 Strengthen older carers' capacity to care for infected and affected persons, and to protect themselves against HIV and opportunistic infections

The first desired outcome in the framework calls for the capacitation of older carers to carry out their caregiving responsibilities optimally and with the least strain on themselves, and to protect themselves from HIV infection and opportunistic diseases contracted through caregiving.

Basis for action

Evidence shows that older persons affected by HIV and AIDS need to be supported on multiple levels. First and foremost, they need to have access to information and resources on how to care for a PLWHA, and how to protect themselves from HIV infection and contain the spread of the disease. Crucial resources required in this regard include protective materials, psychological or emotional counselling, and social grants (grants for which household members may be eligible). However, older carers should not be viewed as passive recipients of resources made available to them, but as active participants and stakeholders in the planning and implementation of appropriate programmes. Such action on their part, and such recognition of their contributions on the part of other stakeholders, will enhance the carers' self-esteem, and ability to cope and contribute. Thus, older carers can become full partners in the fight against HIV and AIDS, and in the management of the effects of the epidemic.

Policy recommendations

- Government policy makers should review current policy and programme intervention on HIV and AIDS, to establish the extent to which the policies and programmes are inclusive of older carers, and provide support to address the carers' specific needs.
- Government should provide information, counselling, support and life skills training for older carers to empower them and enhance their caregiving. Joint efforts between the government and NPOs working to mitigate the effects of the disease in communities should provide age-group appropriate information and counselling services for older persons.
- Older carers' level knowledge on the sexual transmission of HIV should be complemented with the provision of additional information on the non-sexual transmission of HIV to older carers.

- The government should provide essential supplies to older carers for their universal protection. (latex gloves, plastic aprons, disposable napkins and sanitary containers, etc.).

Indicators

- The number of age appropriate information materials developed and distributed to educate older persons on HIV and AIDS. This indicator is designed to measure equity in terms of HIV and AIDS education and information distribution between the different population age groups. As HIV and AIDS is the country's most important Public Health problem, it is crucial that all sections of the population have equal access to recent scientific information, in a popularised format, on the disease. An indicator of equity can be measurement of the development of and access to information packages on HIV and AIDS by older persons. Information needed to formulate this indicator could be retrieved from reports of VCT centres and other health service points at district level. The indicator could be calculated according to *ratio of share of HIV and AIDS materials dedicated to older persons to share of total materials of HIV and AIDS information distributed.*
- The number of district health service points with dedicated staff to counsel, test and support older persons on HIV. This indicator also measures equity in health service accessibility for older persons. The indicator could be measured by *counting the number of health districts service points with dedicated staff to counsel and support older persons on HIV and AIDS.*
- The proportion of older carers with piped water and a flush toilet inside their dwelling. This indicator measures accessibility to local government services. The indicator could be calculated by *counting the number of older persons' dwellings in a district with piped water and an inside toilet compared to the total number of dwellings with similar facilities per district.* The data to calculate the indicator may be retrieved from district municipal records or monthly reports.

6.5.2 Improve access for caregivers to essential services

Many older carers lack basic services such as piped water and flush toilets, especially in rural areas. A lack of such facilities makes caregiving activities even more difficult for them.

Basis for action

Several older carers have difficulty in accessing health service points and providing a nutritious diet for their dependents, and lack piped water and flush sanitation in their

dwelling. Inaccessibility of health care services, or a lack of basic health infrastructure makes caregiving even more difficult for older carers and contributes to the strain and stress they experience. An inability to provide adequate nutrition for a PLWHA may result in more rapid deterioration of the PLWHA's condition, since the body needs proper nutrition to rebuild itself and to enable treatment to work effectively. Children (OVC) need good nutrition to thrive and perform well at school. The Declaration of Commitment of the UN Special Session on HIV/AIDS calls for increased access of vulnerable children to essential services and parity. As a signatory to the declaration, the South African government thus has an obligation to provide equitable services to households with vulnerable children, such as those affected by the disease. The provision of medications, food and nutrition education through home-based care and support programmes can benefit both caregivers and their dependents, and help to sustain the carers' contributions. The accessibility of social grants for which household members may be eligible must be improved, and the means test reviewed and/or disregarded where it denies a vulnerable household access to grants. Unemployed older carers who neither benefit from a social pension should be given rebates on utilities and residential tax relief. However, the old age grant was not designed to cope with the effects of disease such HIV and AIDS, but to cater solely for the basic needs of the beneficiary. Moreover, the data from this survey suggest that the amount of the grant is insufficient, and hence the recommendations in this regard.

Policy recommendations

- More humanitarian policy is needed to ensure that basic health care and nutrition services are available to older carers and their household. In rural areas, government agriculture departments could assist affected households with soil tilling equipment and seeds, to enable the carers and able-bodied household members to work their fields or gardens and grow fruit and vegetables for household consumption.
- Municipal officials charged with the provision of houses to needy persons in communities should assess older carers' dwellings, and assist where home improvements are required, such as room extensions, and the installation of piped water, indoor sanitation and improved ventilation.
- Joint action between NPOs, religious bodies and the government is needed to strengthen district planning efforts through an identification of bodies or individuals sympathetic and

working towards the well-being of older persons, who in turn may be involved in planning and implementation activities, to benefit older carer headed households.

Indicators

The percentage of health service points with health professionals trained in geriatric care. This indicator measures access to health services at the district level in relation to older persons' health care needs. "Geriatric care" is defined here broadly to refer to comprehensive and quality care to older persons. Such care refers to all that happens in older patients' encounters with the health system, including staff attitudes, assistive devices provided, the availability of drugs, and so on. The indicator could be measured by *calculating the number of health professionals with training in geriatric care divided by the total number of health professionals with other qualifications for primary health care services delivery at district level.* However, it has been argued that training on its own does not translate into implementation (Charlton et al., 2009). Data to calculate the indicator may be sourced in human resource records at the health service point. The structure(s) that should be responsible for such incentives and training could be the Department of Health's Public Health directorate under the sub-directorate chronic disease management, disability and geriatric care collaborating with the Departments of Education and Social Development's older persons' programme in conjunction with medical schools.

- The number of health service points with age-friendly environments, including accessible walkways and entrances for the convenience of older clients, per district. This indicator measures the physical accessibility of buildings to older persons. It may be calculated by *counting service points with low pavement, and unobstructed and smooth walkways for easy access for older persons.*
- The percentage of older carers living within X km from a health service point that operates 24 hours a day. This indicator measures the accessibility of health services to older persons. Access refers here to a lack of physical or economic barriers to care services, such as distance and inability to pay for health care. The indicator could be measured by *calculating the proportion of older persons living within X km (10 km radius as per WHO recommendation) from a public health service facility.* Data to populate this indicator could be obtained through a small survey on the health care needs of older persons in a particular district.

6.5.3 Involve older carers in the development of HIV and AIDS policy

Older persons should participate in matters concerning their development and become involved in efforts to fight and manage HIV and AIDS. Older persons should be viewed moreover as contributors to such efforts and not simply as older persons and hence a burden to society.

Basis for action

Older persons' roles and contributions to the care management of the epidemic must be recognised and supported, so that their caregiving capacity may be enhanced, and they are enabled to continue these roles and sustain their contributions. Such a tenet is in accordance with the UN's Madrid Plan (UN, 2002a). The plan outlines older persons' expectations, within the context of a society's economic needs, and calls for their enablement to participate in the economic, political, social and cultural life of their community. It provides specifically for the recognition and support of older persons' contribution to the fight against the epidemic. Moreover, the plan provides for concrete actions to be carried out by various stakeholders to realise its objectives.

Policy recommendations

- Government departments need to review and reformulate policy, and their strategic plan and programmes, to ensure that older persons, older carers in particular, are neither excluded nor discriminated against, especially in the areas of health, HIV and AIDS education and information, and housing.
- Affected households should be encouraged to access other social grants for which they are eligible, such as the child support grant, a foster care grant and a care dependency grant. In addition, the disability grant is available to eligible AIDS afflicted household members. Older carers should be helped to access grants, through assistance with gathering required documentation, and overcoming bureaucratic barriers and delays.
- Government departmental budgets should ensure they provide for programmes to support older carers' households, such as the provision of nutritious food for the PLWHA and OVC, waiving of school fees, monetary help with other school expenses, and so on. Government policies and programmes that support PLWHA should aim to strengthen family cohesion and solidarity, by providing means and support to keep orphaned children within a family environment and in their community.

- Government departmental policies should take into consideration older persons' needs in general, such as age friendly public spaces, public transport and other services, to ensure the well-being and independence of older persons.

Indicators

- The number of older person representative organisations that participate in relevant policy formulation processes each year. The indicator assesses the process of policy development and seeks to establish how inclusive the process is of key role players in the community. This indicator could be calculated by *the number of older person NPOs participating in policy formulation by the total number of other role players participating in policy development each year*.
- The number of PLWHA receiving a disability grant each year. This indicator measures accessibility of government support services to persons in an advanced stage of AIDS related illness. This indicator could be calculated by *counting the number of eligible PLWHA receiving a disability grant per district each year*. The data to calculate this indicator may be accessed from the Social Development department's quarterly or annual reports.
- The number of government departments allocating budget for older persons' needs. This indicator relates to financial planning by different government departments to address older persons' needs, at both national and provincial levels. The indicator may be calculated by *totalling government department budgetary allocations for older persons, divided by the total number of government departments at provincial level.*
- The number of older carers who pay school fees per annum. This indicator measures accessibility of government information (i.e. exemption of older primary carers from paying school fees in public schools) to older persons who are primary carers to grandchildren in school. The indicator could be calculated by *counting the number of older carers who pay school fees divided by the total number of parents who pay school fees per annum per district*. Data to calculate this indicator could be accessed from education departments' annual reports.

6.5.4 Co-ordinate activities to support older carers at the district level

The co-ordination of various activities to support older carers at the district level is fundamental to a mobilisation of their energy, and the contributions of various stakeholders, and the channelling of resources to households in need of support.

Basis for action

As more people become infected with the HI virus and AIDS related mortality increases, district governing bodies experience decreases in labour productivity, an increased demand for services, lower user capacity to pay for services, greater household vulnerability and increased numbers of vulnerable clients (older persons, OVC and PLWHA). District management needs to be supported by provincial and national government to be able to deal with such effects of the epidemic. Since districts are the government bodies closest to affected communities, they are in a unique position to identify vulnerable households, and to co-ordinate responses designed to mitigate the effects of the disease and implement prevention strategies. Clearly, district governing bodies cannot continue with "business as usual" in light of the effects of the AIDS epidemic (World Bank, 2003). Thus, new approaches are called for, on the part of district managers, which may include inviting and engaging other role players in the district regarding policy and programme development and implementation to support older carers and their households.

Policy recommendations

- National government needs to provide training in policy development and implementation for district personnel, to enable them to identify and put older persons' needs on policy agendas.
- Non-profit organisations working with affected carers should educate district officials on the plight and vulnerabilities of older carers and their household as a result of the disease, for them to gain understanding and to elicit their support for older carers' needs.
- District managers should ensure that district services reach vulnerable households, through consultation with NPOs, community based organisations and religious bodies that work with older carers.
- Provincial government should establish co-ordinating mechanisms between role players (NPOs, religious bodies, the private sector, the mass media etc) at the district level to facilitate an exchange of information (of services available to older persons) and collaborative efforts, to prevent duplication of efforts in the support of carers.

Indicators

- The proportion of district managers trained in policy development and implementation. This indicator measures the extent to which managers at district level are capacitated to drive and participate meaningfully in policy development and implementation processes. The indicator could be calculated by *determining the number of district managers trained in policy development compared to the total number of managers from both national and provincial levels trained per year.* Such information may be sourced from district managers' monthly or quarterly reports on staff capacity development.
- The percentage of older person households receiving full municipal services per year. A service accessibility measure, this indicator measures the extent to which older carer households have access to municipal services such as a safe water supply. The indicator may be calculated according to *the number of older person households receiving full municipal services by the total number of households receiving the services per year.* Data to calculate the indicator may be sourced from municipal records.
- The proportion of health districts with a working partnership between district management and NPOs representing older persons per year. This indicator measures the percentage of health districts with a working partnership and could be calculated by *determining the number of meetings and/or workshops held between NPOs representing older persons and district management to address older persons' needs compared to the total number of meetings the district management held with other role players per year*. The information may be obtained from district monthly or quarterly reports.

6.5.5 Avoid ageism, stigma and discrimination

The problems of ageism, stigma and discrimination faced by older carers in their communities, and to an extent in public institutions, are a cause for concern, and call for concerted efforts by all concerned to address and overcome them.

Basis for action

Awareness campaigns are needed to target community leaders who can convey key messages to diverse groups of people. Leaders may include district managers, representatives of community newspapers, religious leaders, sports personalities, youth leaders, community based organisation managers and others. Research findings could be presented in inclusive

community meetings and/or workshops, to educate and encourage community leaders to understand problems of ageism, stigma and discrimination with which older carers must contend. Such campaigns may help to obviate discrimination on all levels. Older persons may be invited to relate first-hand experience of discrimination against them in their community, health service points and other public institutions.

Policy recommendations

- Community leaders such as religious persons and youth leaders should talk openly about HIV and AIDS and on behalf of affected older persons, in order to bring their plight to the public's attention and to generate broad support.
- Non-profit organisations, religious bodies and other relevant community structures should help to identify, but not single out, older person households made vulnerable by the disease, and help to mobilise community response to support such households.
- Intervention programmes developed jointly by the government and NPOs should ensure that vulnerable older person headed households affected by the disease are not singled out, but that services are directed to all residents of a community rendered vulnerable by the disease. Community organisations working against HIV and AIDS should promote de-stigmatisation of the disease within communities by targeting information campaigns to, and providing counselling for, all family members.
- The number of workshops, public meetings and campaigns organised by community leaders through their NPOs to address issues of HIV and AIDS stigma and discrimination per year. This is an output indicator, and may be calculated by *measuring the volume of activities or actions taken by government or NPOs to realise a set target.* Information upon which to calculate the indicator may be extracted from NPO records or annual reports.
- The proportion of affected older person households identified and assisted to access government services through community efforts. This indicator measures access, and may be calculated by *counting the number of affected older persons' household to the total number of affected houses in general assisted by NPOs per district per month.* Data to populate the indicator may be obtained from NPO monthly or quarterly reports.
- The number of public institutions with dedicated advice and complaints offices for older persons. This is an age friendly outcome indicator, and may be populated *by*

counting the number of public institutions with dedicated age friendly offices per district.

6.5.6 Engage in dialogue with traditional healers/practitioners on HIV and AIDS and older carers

An estimated 200 000 traditional practitioners (of all categories) operate in South Africa and work parallel to the mainstream Public Health sector. The government is currently engaged in dialogue with these practitioners and is developing mechanisms to monitor their work.

Basis for action

Traditional healers practise in communities where poverty, HIV and AIDS co-exist. The role they play in the fight against the epidemic has been at variance with the mainstream approach, as was noted in the case studies. The practitioners seemingly do not share an orthodox understanding of the disease. Some argue, for example, that they can cure the disease through the use of traditional preparations. In the process, however, they charge clients, among whom are older persons, exorbitant fees for treatments; older clients invariably have scant resources which they deplete in this way, in desperation, in search of a cure. Traditional healers need to be educated about the vulnerability of older clients and the limitations of their healing powers. It is essential therefore that they be included in the mainstream Public Health approach to the management of the disease, to prevent confusion about their ability to heal, or indeed cure AIDS among vulnerable sections of the population. Traditional healers are familiar with their community's culture (the belief system, traditional practices, spiritual inclinations, and so on), and therefore potentially constitute a valuable resource to counsel older clients on HIV and to promote adherence to prescribed orthodox treatment regimens. Moreover, the practitioners need to be educated to refer HIV positive clients to Public Health service points for diagnosis and treatment.

Policy recommendations

- Involve traditional healers in the mainstream Public Health approach to the management of the epidemic. Avoid contradiction between information provided in Public Health messages on HIV and that provided by some traditional healers, by engaging the practitioners in dialogue.

- Capacitate traditional healers through dialogue and educate them on the causation and spread of the disease. Inform them that HIV is dissimilar to other sexually transmitted infections which they commonly manage in their communities, and is therefore incurable. Encourage them to not give false hope to desperate and vulnerable affected persons such as older carers about their ability to cure the disease.
- Help traditional healers to counter myths about the disease, and to promote responsible attitudes and behaviour towards the epidemic and avoidance of infection. Encourage them to promote HIV testing and the use of condoms, and lifestyle behaviour change as a main way to prevent the spread of HIV – rather than merely sell herbal preparations to vulnerable clients.

Indicators

- The number of traditional healers educated on HIV and AIDS by the government at the district level. This input indicator may be calculated by *counting the number of practitioners educated on HIV and AIDS per district*. Data for this indicator may be obtained from district health information systems or clinic records on community outreach programmes that focus on training of community organisations on HIV and AIDS.
- The number of traditional healers educated in VCT counselling per district per year. This is an input indicator, and could be calculated by *counting the number of traditional healers trained as VCT counsellors per district.* Data may be obtained from VCT service points.
- The number of HIV and AIDS clients referred by traditional healers to district health service points. This is a systems indicator, and measures the effectiveness of traditional healers' referrals to Public Health service points. The indicator may be calculated by *counting number of referrals made by traditional healers to health service points in relation to HIV and AIDS within districts per month.* Data to populate this indicator may be obtained from health clinic referral records.

6.5.7 Identify and assist with older carers with their need for adequate shelter

Older carers' stated need for adequate shelter featured prominently in outcomes of the survey and case studies in this dissertation, and warrants urgent attention from the government.

Basis for action

It is accepted that the government is unable to address all infrastructural development needs overnight, but it remains responsible for addressing housing needs. It equally remains a key role player and leader in responses to the effects of the epidemic. Young children rendered vulnerable or orphaned by the epidemic often move into the home of their grandparents, but the dwelling is often sorely inadequate and overcrowded. The government needs to set legal and policy mechanisms in place to ensure that national and international resources are mobilised to address the shelter needs of affected older carer households and vulnerable children urgently. NPOs as critical role players should assist the government to do so by identifying affected older carers, who should be given preferential consideration in the delivery of affordable and adequate housing, or at least whose dwelling should benefit from home improvements.

Policy recommendations

- Provincial government should give directives to high ranking officials, who with the assistance of caregiver NPOs should draw up a plan of action to speed up housing delivery for older carers' households.
- National advocacy NPOs need to strengthen efforts to increase older persons' access to credit and housing loans, especially those trying to cope with effects of the epidemic.
- Older carers are not only at risk of infection with the HI virus, but are exposed to opportunistic infections such as pulmonary tuberculosis. The provision of more spacious and better ventilated houses will help to reduce the spread of contagious opportunistic infections in this sub-population. Indoor piped water and flush toilets are crucial for optimal hygiene and facilitating caregiving.

Indicators

- The percentage of affordable and sufficiently spacious houses allocated to older caregivers per district per year. This indicator is an equity indicator, and measures accessibility of affordable decent housing provided by the government to older caregivers compared to other groups in the community at the district level per year. The indicator may be calculated by *counting the number of affordable houses allocated to older carers in a district by the total number of affordable houses allocated per year in*

a district. Information to populate the indicator may be obtained from the district housing department's records.

- The percentage of older persons accessing credit and/or housing loans per year. This is a service access indicator, and measures accessibility of credit and home loans to older persons. The indicator may be calculated by *counting the number of credit and housing loans made available to older carers proportionately compared to the total number of credit and housing loans provided by banks per year*. The information may be accessed through banks' monthly or quarterly reports.

6.5.8 Promote age-friendly district health service points

A recent worldwide trend in health service provision, introduced by the World Health Organization, is the promotion of age-friendly health district services to meet the health care needs of older persons equitably, especially those living in isolated poorly serviced rural areas.

Basis for action

While the government makes special provision for health care services to specific population age groups, such as the youth, children and expectant mothers, at the district level, it provides no dedicated geriatrics services for older clients which are desirable. Older persons have specific health care needs, especially relating to chronic ailments, and have physical and cognitive impairments. Older carers' health is seriously compromised through the strain of caregiving. National and provincial government thus needs to plan, in consultation with NPOs and district health managers, to provide dedicated health care services to older clients, with specific consideration given to the chronic health conditions and vulnerabilities of older carers. Such needs embrace basic health care, nutritional services, welfare services, dental care, eye care and other essential services. The services should be delivered in age-friendly environments. District level managers should commit themselves to policies that sustain older carers' capacity to support themselves and others in their household.

Policy recommendations

- National and provincial government should promote age-friendly health service points at the district level. Features of such environments may include accessible seating; signage in large lettering and local languages indicating facilities such as the pharmacy,

dressing room, social worker and dentist; and separate appointment and referral systems for older clients.

- Provincial government should discourage age discrimination in vital services such as primary health care services voluntary counselling and testing (VCT), and education on HIV and AIDS at community health centres.
- National and provincial government should train health care providers at the district level in the management and prevention of age related physical health conditions, such as hypertension and arthritis, and mental illnesses such as depression, stress and insomnia.
- Provincial and district government should improve the availability and supply of medicines to treat health conditions commonly found in older persons at district level health service points.
- Older persons' health support groups need to be established at district health service points, to provide co-counselling with treatment use and adherence, especially in the case of chronic conditions.

Indicators

- The number of health service points with age-friendly environments per district. This indicator measures accessibility of health service points for older persons within districts. The indicator could be measured by *counting all health service points that meet the above criteria within the district.* Data to populate the indicator may be obtained from health service point infrastructure design reports and by physical inspection of the facilities.
- The proportion of health service points with effective referral and appointment systems for older persons per district. This indicator measures systems performance, and assesses whether the referral and appointment systems benefit older patients insofar as services at the receiving health facility are readily available, and clients/patients are not turned away owing to unavailability of services, incorrect appointment times, and incorrect or inappropriate referrals. To populate this indicator one may have *to interview health service providers, but who tend to exaggerate the availability of services, or how adequate the referral or appointment system is.* Hence, one may need to randomly select recently referred older clients to the health service point and interview them.

- The number of older persons serviced at dedicated clinics per district health facility per month. This is a quality measurement indicator, and measures health service performance *vis-à-vis* provision for the health needs of older clients. Information gathered to populate the indicator may be used for district health service reform, and may be obtained from monthly or quarterly health service points reports.

6.5.9 Raise awareness and advocate for community mobilisation to create a supportive environment for older carers

Awareness raising through mass meetings, and the dissemination of literature and mass media broadcasts, especially over the radio, have a potential to draw the attention of a wide and diverse audience to the plight and support needs of older carers. Such strategies should be pursued aggressively to garner support for older carers. In this regard, social marketing which combines traditional marketing approaches, new technology, as well as integrated action and planning for social change is recommended (Kotler & Roberto, 1989).

Basis for action

The impact of HIV and AIDS on older carers, their family and community is multifacetted and cannot be addressed by any single sector (public, private or community) alone. HIV and AIDS related situations therefore call for awareness raising among the public at all levels. Advocacy based on empirical evidence on the havoc caused by the epidemic on the lives of older persons and their households is needed urgently, so that appropriate responses may be designed and implemented, and supportive environments created for the carers and their households. Social marketing has been used in several SSA countries (e.g. the Democratic Republic of the Congo, Kenya, Lesotho and Zimbabwe) to retard the tide of the epidemic (PSI, 2005) with some success. Previous communication campaigns by Soul City and LoveLife were shown to influence behaviour change in relation to HIV and AIDS, fight stigma and generate support for PLWHA in South Africa.

Policy recommendations

- Government and NPOs at provincial and local levels should link HIV and AIDS prevention, care and support activities for PLWHA and OVC with responses to the support needs of older carers, to ensure that all affected household members are targeted in intervention.

- Government and NPOs should develop appropriate social marketing tools to address the effect of the epidemic on affected older persons.
- NPOs and the private sector should encourage and support local initiatives, such as support groups that promote community and family solidarity, to withstand the direct and indirect impact of the disease on households.
- The government could provide physical space in under-used government property for support groups to meet and discuss issues relating to HIV and AIDS. Government at national and provincial levels should make use of its vast resources (personnel; infrastructure, funds, etc.) to disseminate examples of successful experiences and lessons learned in raising awareness on the plight of older carers.
- Social marketing using mass media (e.g. TV, radio, pamphlets and billboards) and interpersonal communications strategies which are culture based and targeted at intended audiences.

Indicators

- The number of joint public gatherings or awareness campaigns held between government, the private sector and NPOs designed to highlight and address the plight of older carers per year. This is an output indicator measuring collaborative efforts between the different role players at the district level. The indicator may be calculated by *counting the total number of the joint gatherings per year*. Information to calculate the indicator may be obtained from the NPO and/or local government annual reports.
- The number of information documents (booklets; pamphlets; flyers, posters, etc.) distributed by the government on successful efforts to raise awareness about older persons' plight issued per district per year. This indicator is an input indicator and measures efforts to highlight the plight of older persons at a community level. The indicator may be calculated by *counting the number of documents distributed per year*. Information may be obtained from NPO records or annual report and or government annual report.
- Number of television and radio programmes providing information on HIV and AIDS directed at or inclusive of older persons.
- Number of billboards and educational materials displayed in public spaces.

The indicators suggested in the policy framework do not cover the full spectrum of those that could be used conceivably to measure the performance of different stakeholders in planning and provision to meet older carers' support needs. Some indicators may be used to measure more than one activity outlined in the framework. However, the use of the proposed indicators will rely on role players to gather and record activities throughout the year, so that performance and trends of service point activities can be measured. A plan of action to guide the use of the framework is proposed below.

6.6 PLAN OF ACTION TO GUIDE EMPLOYMENT OF THE POLICY FRAMEWORK

The policy framework outlined above provides a basis for the review and reform of relevant policy, to meet the support needs of older carers, and offers policy recommendations and indicators to measure implementation outcomes of new policy and programmes. Government policy makers may scrutinise the policy framework, and after consultation with relevant role players, may take decisions to:

- Review existing relevant policy and programmes to ascertain the gaps in supporting older carers and their dependents (i.e. PLWHA and OVC).
- Engage with stakeholders in the formation of a working group to design best strategies to address, or alleviate the carers' plight.
- Re-assess the situations of older carers and their households, primarily a responsibility for NPOs, to determine support needed, and the scope and effectiveness of existing responses.
- Consider how the support needs of older carers could be mainstreamed in existing policies and programmes, or whether there is a need for new dedicated policy and programmes to support the carers and their households.
- Design a comprehensive strategy on how to address the gaps in government policy and programmes and older carers' needs and how such a strategy could or should involve older carers or their representative organisations.
- Identify resources required by various role players: budgets, time, staff, volunteers, infrastructure, etc., to implement policy actions and achieve desired outcomes. A

realistic assessment of role players' capacity will assist them to focus their energy and resources on what is achievable within a specific time frame.

NPOs whose input will be potentially crucial in the various processes include Age-in-Action, Grandmothers Against Poverty and AIDS (GAPA), Neighbourhood Old Age Homes (NOAH), the South African Older Persons' Forum (SAOPF), the South African Red Cross Society and the Muthande Society for the Aged (MUSA). Another NPO is Catholic Welfare and Development (CWD), whose focus is on community development in general, and deals with issues of women empowerment and provides services to the vulnerable and marginalised sections of society, among whom are the poor, homeless and unemployed within the Western Cape Province. CWD works to empower the youth, women, refugees, the elderly and those living with HIV and AIDS. Other NPOs that may be involved are the Nelson Mandela Children's Fund and the Desmond Bishop Tutu HIV Foundation, both of which empathise with older persons.

Functions and tasks of various stakeholders, or role players may include:

- The appointment of a working group by the government, in consultation with stakeholders, to identify a role player(s) to drive one or more desired outcomes proposed in the framework.
- The compilation of examples of successful, relevant community responses to the epidemic, such as home based care programmes (e.g. Red Cross Society), community health and rehabilitation workers (e.g. Zibonele Community Health Project), by NPOs that serve older clients as best practices for replication by relevant role players.
- Consultation with the private sector being on roles it might play and contributions it could make. Commercial banks could be approached to revise discriminatory home loan and credit policies that exclude older persons who wish to improve the condition of their dwelling. Older carers may want to borrow money from a bank to buy a new and bigger house for their family.
- Consortia of government departments at provincial level and other stakeholders could mobilise and ensure optimal utilisation of resources (financial, human, infrastructural and knowledge related) to achieve desired outcomes. Ways in which role players may be involved in resource mobilisation could include i) the government facilitating and co-ordinating other role players' activities, and various government departments providing budgetary allocations to support the realisation of the plan; ii) non-profit

organisations offering dedicated support programmes for older persons, such as income generation skills development and food gardening programmes; and iii) religious bodies offering emotional counselling, and providing physical space for support group meetings, training, and skills development activities (e.g. income generation; budgeting and networking).

Supplementary information needed to support the development and implementation of new policies and programmes informed by the policy framework is considered below.

6.7 INFORMATION NEEDED TO INFORM APPROPRIATE POLICY AND PROGRAMME DEVELOPMENT AND IMPLEMENTATION

The plan of action provided is intended to guide the role players specifically in the employment of the framework. However, settings are varied and situations are fluid, and policies, strategies and programmes that emanate from consultation and indeed adoption of the framework may need to be informed by supplementary and context specific information. Such information may need to cover areas and be elicited through actions such as follow:

- A determination of prevalence rates of HIV in older persons and older carers' risk of infection in various provinces and locations.
- An exploration of opportunities and information needed to establish working relationships between district management and older persons' NPOs, with a view to joint action to support older carers, such as information and education on HIV and AIDS.
- A determination of the nutritional needs of older carers, PLWHA and OVC, as a basis for their inclusion in food support programmes.

The policy framework is mainly shaped by the empirical evidence garnered from the respondents. A challenge that lies ahead is how policy and strategic plans may be directed to and taken up at district levels, where the study population is located, and is largely ignorant of available government services. A lack of food, one of the greatest support needs identified, is critical in the majority of this population's households. In addition, the availability of food is crucial in the management of HIV and AIDS.

6.8 EVALUATION OF THE APPROPRIATENESS AND FEASIBILITY OF THE POLICY FRAMEWORK

The policy framework developed in this chapter is designed to assist role players in supporting older carers affected by the HIV and AIDS epidemic in South Africa. The framework highlights the central role that government must play at all levels in facilitating and co-ordinating the activities of different role players at the district level in this regard. A strength of the framework may lie in its inclusive approach, which aims to involve all role players – government departments, non-profit organisations, religious bodies, traditional healers, the private sector, academic institutions, the media and older carers themselves – in the review, and reformulation, or development of new policies and programmes to address older carers' needs specifically, but in an integrated way. The framework aims to build bridges within and across formal and informal sectors of society, and within and outside of government departments. A strategy plan that may be developed by stakeholders, informed by the framework, could serve to improve stakeholders' access to resources and provide for a more efficient use of resources and greater acceptability of policies and programmes. A strength of the framework lies similarly in its being based on empirical evidence, as against theoretical argumentation, and its argument for a bottom-up approach to public policy development.

A limitation of the framework may be its reliance on a political willingness of the government to adopt the framework and implement its recommendations. The framework will compete for the government's attention with the needs of other more vocal interest groups in society, such as trade unions, gender groups and youth groups, all of which are better organised than older person groups. The adoption, or employment of the framework as a guiding tool will therefore depend on the willingness of politicians and policy makers to recognise the extent of older carers' plight and the urgency of their needs.

The proposed policy framework recommendations are not a panacea for all problems of service inaccessibility experienced by older caregivers. The recommendations are made rather with a view to strengthening or enhancing what infrastructure and services are already in place. It is not disputed that the South African government already does a great deal for indigent older citizens through the grant system (see Moller & Sotshongaye, 1996; Sagner & Mtati, 1999**).** However, insufficient or poor accessibility of services for older persons,

because of barriers such as a lack of affordable transport to access health care, prevails in non-urban areas especially. Research indicates moreover that entry points to health services points must be barrier-free (WHO, 2004; Fitzpatrick et al., 2004). Physical and service delivery barriers need to be removed to enable older persons with temporary or permanent functional limitations to access needed care, and to maintain health and independence. Age-friendly public health facilities at the district level can help to sensitise and educate health providers about the specific needs of this section of the population.

CHAPTER SEVEN: CONCLUSIONS, EVALUATION AND RECOMMENDATIONS

7.1 INTRODUCTION

In this chapter, conclusions of the dissertation and empirical study are drawn, the hypotheses are confirmed, the study and dissertation are evaluated, and recommendations are made for future policy and research in the subject area. Specifically, and broadly rather than sequentially, I reflect on the results of the empirical study; discuss findings of the study and the dissertation; evaluate how the mixed-methods approach enabled an identification of concerns and difficulties experienced by older persons in the course of caregiving to PLWHA and OVC; and make recommendations pertaining to a role for primary health care (PHC) to address older persons' health needs at the district level, as well as to areas in which further research is needed. The recommendations are made for the consideration of all stakeholders involved in the fight against HIV and AIDS, and who are concerned about or tasked with providing for the health and well-being of older persons in the SSA sub-region and in South Africa specifically. Among relevant stakeholders are government departments, NPOs, CBOs, FBOs, traditional healers and the private sector.

7.2 CONCLUSIONS

Conclusions drawn pertain to findings of the study and the dissertation as a whole. I emphasise a need, based on the evidence presented in this dissertation, for older carers to be supported formally: not only as increasingly dependent and vulnerable people, but also to enable them to help themselves – thus, strengthening their capacity to help those for whom they care.

7.2.1 Filling gaps in knowledge

The findings of the empirical study supported prior evidence on several issues relating to caregiving by older persons in the sub-region; the findings also identified a number of new issues about which little is thus far known. Evidence from the empirical study showed, for example, that not only older women are primary carers to PLWHA, but older men as well. Second, the study established how the epidemic in South Africa affects family structures and

family relationships between older members and younger members. Third, evidence was gleaned on the extent to which the effects of the epidemic overwhelm the adaptive capacity of affected households, specifically with respect to household finances and food security. In addition, the dissertation has contributed to gerontological knowledge broadly – and to the development of African gerontology specifically. The dissertation has made out a case for protecting the health of older persons in order to prolong their life and sustain their well-being, and benefit the people for whom they care. The findings affirm the extent and multiplicity of the problems that the disease creates for older carers and their households in the sub-region – and contribute to filling emerging gaps in knowledge.

The study has contributed to knowledge on changing patterns in traditional kin support systems. Although stronger historically in non-urban settings than in urban settings, the structures appear to be weakening under the strain of the epidemics – in both settings. A progressive loss of support capacity of affected households is what prompted numerous caregivers in the study to identify a need for financial support. Indeed, the study has brought most of the determining factors that define the nature of the double burden of caring for an older chronically ill person(s) caring for young children. Interventions such as government policies and programmes to support the carers should thus take into account the levels at which the interventions need to be implemented optimally: i.e. at the levels older carers, their households and their community as a whole.

7.2.2 Filling a gap in Public Health knowledge and practice

The dissertation has established, through the review of the international and regional literature and evidence yielded in the empirical study, that older persons play a valuable role and contribute to primary health care delivery within their household. Where they care for PLWHA and OVC, they are a vital link in the care continuum between a hospital, clinics, the community and a household, even though they may have no formal training in caregiving. Indeed, the majority of older carers simply assume this role by default, because of the non-availability, or a lack of willingness of other family members to discharge such a responsibility.

The dissertation has identified a growing future concern, namely that older persons may be at similar risk of infection as younger people through unprotected heterosexual sex. The number

of older persons in South Africa (Shisana et al., 2006) and the SSA sub-region (HelpAge International, 2008a) infected with the virus is increasing rapidly. Older persons are therefore equally in need of public health interventions such as AIDS information, education, testing and counselling, and other preventive and treatment measures, as persons in other age groups.

The fact that the empirical study found a reluctance on the part of older carers to take their sick child(ren) and/or grandchildren to state health service points is a reflection of their perception that health providers, or the health system, are unable to respond to the evolving health care needs of affected communities. A lack of age-friendly health service facilities at the district level, and thus poor access by and unsatisfactory services for older clients, is a matter in need of redress by the Department of Health.

The study also contributes to knowledge by highlighting the role that older carers play in their community and family as development agents, through their nurturing and educating of young children in their care. The additional contributions made to human and other development in turn contribute to the achievement of Millennium Development Goals (MDGs) in affected countries.

Older persons are in many senses *de facto* health care providers to their households. Their involvement in health care delivery should thus be encouraged and utilised at the district level, provided that they are capacitated with the necessary skills, knowledge and support. Specifically, older persons have a role to play in delivering primary health care relating to HIV and AIDS prevention, care and treatment support and monitoring. Thus, they should be consulted and included in public health intervention programmes, such as HIV counselling and monitoring of treatment use by PLWHA: as peer educators and distributors of condoms, among other roles. They could also play a role in monitoring how older persons are serviced at PHC service points at the district level, such as whether they benefit from the cost exemption policy for older persons.

Involving older persons as community members in the delivery of health services – a central principle of primary health care – will create a sense of ownership among them, of the programmes at their local health clinic. Older persons as a group could serve as a permanent source of support to health service delivery at the district level, although their membership will change intermittently through attrition. They would nonetheless need to be given

periodic support and opportunities for training and for the exchange of ideas and experiences with clinic health staff. They could be an invaluable resource, especially in resource constrained environments, such as rural areas and shanty towns with a dire shortage of health personnel.

7.2.3 Filling a gap in research methodology

Studies of older persons and HIV and AIDS in the sub-region have only been conducted in the last decade or two, and as the review of the relevant literature has shown, have been fairly similar in the small scale and the single setting or research site of the studies. The research methods employed in the majority of these studies have not been particularly innovative, and may have failed, by and large, to give a full picture and understanding of the study population's situation and needs. None of the studies as far as could be established has employed a mixed-methods approach. A contribution of the present study and dissertation therefore lies in the use of a mixed-methods approach and triangulation of data from multiple data sets to understand the multi-dimensionality and complexity of the effects of HIV and AIDS on older carers.

Use of this approach enabled an exploration of the study problem from different populations and perspectives, and on different levels. First, analysis of the survey data provided an understanding of the magnitude of the problem in the delimited settings in the three targeted South African provinces, and of differences in the effects of the disease in urban areas and non-urban areas. Second, analysis of the study data provided an understanding of how the carers perceive their situation, and how in their opinion it should be addressed by the government and other relevant stakeholders. Third, analysis of the key informant interviews data provided the views and understanding of non-profit organisations' managers, government officials on the plight of older persons managing HIV and AIDS and how policy address or does not address their support needs. Finally, triangulation of the data and findings from three data sets provided a comprehensive analysis of the three data sets, where areas of concurrence and divergence were identified. The latter approach also served to show the lack of understanding by government officials of the older carers' burden and support needs.

Hence the dissertation has demonstrated the value of using a mixed-methods approach and a case is made out for its use in future studies in other settings, including comparative studies.

7.3 EVALUATION OF THE DISSERTATION

7.3.1 Contribution to knowledge and society

The dissertation has contributed to knowledge in the subject area through its review and synthesis of a large body of international, regional and national literature, instruments and policies, as well as the evidence generated in the empirical study. A key outcome of this review and study is the documentation of empirical evidence on the effects of the epidemic on older persons, as caregivers to sick and dying children and how they cope with limited support from NPOs and a lack of formal support. The study also showed that some older males, albeit a small number in this sample, are primary carers, contrary to traditionally and culturally accepted roles for males in this society. Another contribution is the identification of gaps in the extant literature, and policy instruments and documents reviewed, and the specific attempts made in the dissertation to fill some of these gaps. Overall, it has been argued that older carers' or their representative bodies' issues and concerns have thus far largely been overlooked in all policy development and intervention. Highlighting this gap may contribute to future policy formulation and reform. Thus, the dissertation and its outcomes can help to put older carers and their support needs on centre stage, especially regarding issues relating to their capacity – and need for support – to be able to render care optimally and cope, and to sustain their own health.

7.3.2 Contribution to Public Health Care

The greater part of the literature on health provision indicates that state health systems in the SSA sub-region do not cater adequately, for the health care needs of older persons, especially at the district level. The dissertation has made a strong case for, opportunities to deliver appropriate and optimal health care to this population – and thus support older carers at the district level. The policy framework proposed in Chapter 6 in this regard identifies a set of potential health indicators to guide and measure successful implementation of appropriate, inclusive PHC programmes – in both urban areas and non-urban areas. The study also highlighted an apparent disinclination of older persons in the Eastern Cape Province to access health care services, compared to counterparts in the other two provinces, possibly because of poor health care infrastructure and barriers to health care in the Eastern Cape, but which finding needs further investigation. The finding nevertheless indicates a need for improved health care services for older clients in that province, and indeed countrywide.

In addition, the dissertation has highlighted the desirability of older persons' or their representative organisations' direct involvement in the monitoring and evaluation of the implementation of policy provisions: both those that affect them and those relating to HIV and AIDS in general. Practical steps that may be taken to involve older persons in such activities could include development of a standardised protocol for their inclusion and participation in such policy processes. Such a practical tool may serve as a guide to senior district health managers on how to work with older persons or their representative organisations, and in which ways.

Identification of the health care needs and participation of older persons as primary carers in communities and households contributes to an understanding of the needs (e.g. information, education and training, and skills development) of these lay primary health care providers. Indeed, recognition that older persons render home care in their community may be a valuable entry point for public health care programmes to support older carers. The policy framework proposed in Chapter 6 can serve as a tool to be consulted by various role players at the district level to identify and act on issues relating to the needs of older carers and older persons in general: for example, improve their accessibility to health services, and provide them with safe water and suitable sanitation.

The dissertation promotes the principles of primary health care, such as PHC as a collaborative effort between all relevant role players, which can help to build links with other support services and facilitate timely referrals of older persons and/or their charges to other levels of care within a continuum of health care.

Obstacles remain in the development and implementation of programmes to meet older persons' and older carers' health care and support needs. These obstacles include a scarcity of resources – financial, infrastructural and human, and a negative mindset towards older clients on the part of health providers towards older persons. Ultimately, older persons – or older health care clients – must not be perceived as a liability, or a drain on health resources, but as contributors to the well-being of others in their community and households (Ferreira et al., 2007). Indeed, their contributions, capacity and wealth of experience need to be harnessed and sustained, and applied and utilised for the benefit of all.

7.3.3 Application of theory

The development and employment of an analytical and explanatory theoretical framework for the study, drawing on social exchange theory and feminist theory, enabled an application of theory in an investigation of caregiving by older persons in response to HIV and AIDS in a developing country, in this case South Africa. The theoretical applications highlighted the disproportionate caregiving burden on older women, and their comparative gender related disadvantage in several domains, as well as the dynamics of intergenerational caregiving behaviour, and which actors benefit (or may not benefit) at particular stages, and how and why.

7.3.4 Application of research methodology

The empirical study employed a relatively large survey sample which covered three provinces and was recruited in both urban settings and non-urban settings. The research design provided for the use of both quantitative and qualitative research data collection methods, with an aim to generate information towards an understanding and elucidation of the demands of caregiving and the challenges for older carers. The mixed-methods approach, which incorporated triangulation of the data from the three data sets, employed helped to fill a methodological gap left in the majority of earlier studies in this problem area, elaborated in the dissertation. The application of a mixed-methods approach enabled the researcher, methodologically and substantively, moreover to meet the study's objectives: Specifically, i) a determination of the nature and burden of care on older caregivers in households affected by HIV and AIDS; ii) an identification of the financial, physical, social, emotional and health care needs of older caregivers, as well as factors facilitating and hindering caregiving, such as a lack of financial resources; iii) an assessment of how various role players at the district level can work together to support older person households affected by HIV and AIDS; and iv) the establishment of extensive evidence for policy makers and programme planners, to inform them in the design and implementation of appropriate policies, strategies and programmes for the benefit of older carers.

However, while the study and dissertation conceivably achieved the objectives that were set, areas in need of further research were identified in the course of the work, which are outlined in sub-section 7.5.3 below.

7.4 RECOMMENDATIONS

The three hundred and five older persons who participated in the study constitute only a "tip of the iceberg" in the picture that they provided of the immense suffering and vulnerability of older carers in South Africa and other sub-regional countries. Numerous recommendations to improve their situation and reduce their burden were made within the policy framework proposed and outlined in Chapter 6. Additional recommendations, of a broader or more specific nature, are made below.

7.4.1 Towards improving older carers' quality of life

It is crucial that older carers' situations are improved, through support from the government and other role players. The dissertation has demonstrated that interventions to achieve this goal may be best effected through public health agencies at the district level. Enhanced quality of life for older carers can serve indirectly to improve the health and well-being of those in their care.

Specifically, older carers' quality of life may be enhanced by improving their access to essential services, such as health care, safe water and the removal of bureaucratic barriers – for example, where they need to obtain legal documents. Although the majority of the carers surveyed received an old age grant, the amount of the benefit was shown to be insufficient to provide for the needs of multiple household members. Thus, the government might investigate the feasibility of providing care grants to older persons who care for PLWHA and vulnerable children. Besides, helping them to meet the needs of affected and vulnerable children and grandchildren, such a policy, would be in accordance with the Millennium Declaration of Commitment on HIV and AIDS. Such measures, taken together, would go a long way towards improving the carers' quality of life, especially through enhanced physical health, and emotional and psychosocial well-being, and improved ability to cope, while off-setting additional financial burdens they experience.

At the same time it is important that older persons themselves are enabled to become actively involved in addressing socio-economic, development and health issues that affect their lives. Although the older carers' attitudes towards their involvement in health care delivery were not investigated as such, studies conducted elsewhere, e.g. in Asia and the Pacific (see Masulit, 1998; World Bank, 2006; HAI, 2006a), have shown that older persons are eager to

participate in this function. Older persons in the Philippines, for example, were trained as "community gerontologists" to work closely with doctors, dentists and nurses at Primary Health Care facilities (Masulit, 1998). They were later able to perform basic medical checks, keep records and refer complicated cases to health professionals. In numerous other affected countries, such as Thailand and countries in Africa, older persons are already involved, albeit without formal training, in health caregiving, as evidenced through care of their sick children (i.e. PLWHA).

7.4.2 Towards formulating and implementing appropriate Primary Health Care responses

The survey showed that older carers suffer from poor health generally, which is manifested in chronic conditions such as hypertension, arthritis and depression. Thus, older carers need better access to health care services in the public sector, at the district (primary care) level, that can manage disease conditions common in older persons, and in older carers effectively and acceptably to the clients. Such measures should include the establishment of age-friendly health service points at the district level, and the discouragement of age discrimination in vital services such as counselling and reproductive health care. This study has shown that some health personnel at the district level have little understanding of how to relate to older clients and to provide health services that meet their needs.

Additional measures taken should include improved referral and appointment systems for older clients, to enable them to conserve limited time and financial resources. Older clients should moreover not be charged for primary health services. The policy provision exempting beneficiaries of an old age grant from paying a fee for primary health care is frequently disregarded. Health care providers at the district level need specific training in the treatment of age related health conditions, as well as HIV and AIDS in older persons, the symptoms of which, such as muscle wasting and confusion, are often ascribed to ageing and neglected.

While overall levels of awareness and knowledge of key aspects of HIV and AIDS were found to be satisfactory in the sample of older caregivers, credit for such knowledge levels should probably be given to NPOs. However, persistent myths and misconceptions about the cause and management of the disease were still found among some caregivers. The salutary work of NPOs in this regard should therefore be complemented and reinforced through dedicated campaigns drawing on relevant messages from respected older leaders such as Mr

Mandela, Mrs Sisulu and Bishop Tutu. The messages could be conveyed through the mass media (radio in particular), in the languages of the targeted audiences. Such campaigns may help to dispel myths identified in the study. It is important that all aspects of the epidemic, including voluntary counselling and testing, nutrition, treatment, home-based care and human rights, are emphasised in the campaigns.

7.4.3 Identification of further research needed

Further research in the problem area is indicated. In particular, age-disaggregated data need to be collected on the needs and roles of older people, to inform the design of appropriate HIV and AIDS interventions inclusive of older persons and their needs. The impact of poverty on HIV and AIDS related caregiving, as it affects older carers, needs to be linked to national poverty monitoring and evaluation systems of the government, so that an understanding may be achieved of how the two phenomena reinforce one another in affected older-person households. A better understanding is needed of the health seeking behaviour of affected older persons, and to what extent AIDS-related caregiving is a causative factor of their ailments. Finally, the small number of older male carers in the study indicates a need to investigate their situation, at household and community levels, specifically.

The ways in which traditional healers may be engaged and their resources harnessed in the fight against AIDS need to be better understood: specifically, how the healers may be encouraged to work with older carers in appropriate ways (see Peltzer et al., 2005). Evidence based information is needed to guide the design of educational materials on HIV and AIDS, which should be age and gender sensitive, and incorporate the views and experiences of older persons. Finally, forward looking research is needed to determine what the ramifications may be of greater HIV prevalence – and care and support needs – in future older cohorts.

Additional consideration may still need to be given to the development and employment of research methods that will look at the long-term implications of the present effects of the epidemic on communities and households – hence, longitudinal studies. Moreover, more studies are needed on the role of older men as caregivers in AIDS affected households, and *their* perceptions of government intervention(s) to alleviate the burden of caregiving. Importantly, more extensive baseline data are needed to measure progress towards resolution of older carers' problems.

7.5 CONCLUDING REMARKS

It was the researcher's intention that gaps in knowledge identified in the statement of the problem, and the identification of a need for empirical evidence in the problem area, should be filled to a large extent by the evidence generated in the study. The study has contributed in a large measure to filling such gaps, but, more information is still needed on the effects of the disease on older persons in different settings in all of South Africa's nine provinces. In particular, older men whose participation in caregiving receive far less attention compared to their female counterparts with respect to what they contribute, how they are affected and what specific support needs they require given that caregiving historically has been women activity. Crucially, all sections of South African society – and indeed SSA societies – need to participate in efforts to address the support needs of older caregivers, guided by the principles of Primary Health Care (WHO, 1978) and the Universal Declaration of Human Rights (UN, 1948) – such as inter-sectoral collaboration, community involvement, and treatment with equality and dignity. Thus may affected and vulnerable older caregivers and their households be identified more easily, and interventions to support them and meet these needs implemented.

The findings of the study have implications for policy. It was established that present government policy intervention, such as the HIV and AIDS strategic plan and programmes such as voluntary counselling and testing, PMTCT, condom distribution and education information campaigns, lag in addressing older carers' support needs. Moreover, social protection, in the form of old age grants, is inadequate. The existing grants should not have to meet the multiple expenses that older carers must shoulder because of effects of the epidemic and a lack of other formal support. A review of the formulae used to calculate the nature and amount of grants, and whom they are targeted at and for what purposes, is strongly indicated. Improved or expanded social protection for older carers would constitute an important step towards sub-regional governments' fulfilling regional and national commitments to human rights goals for older persons. Similarly, the South African government should review its housing policy for the indigent section of society, inclusive of older persons, as a matter of urgency, and revise the formula for, and fast track the process of allocating houses in which the housing needs of poverty-stricken older caregivers are prioritised.

The undermining of older persons' human rights in the limited information and education on HIV and AIDS available to the older population runs contrary to South Africa's constitutional provisions – in this case, the right to information and education. The government's national campaign on adult literacy should therefore address the education and information needs on HIV and AIDS for older persons inclusively and specifically, applying proven methods and principles of adult literacy programmes, such as respect for learner knowledge and experiences.

In addition, government departments, especially at provincial level, need to work more closely with one another regarding HIV and AIDS and its effects on older persons. The dissertation has shown that provincial health department personnel tend to view the problems spawned by the epidemic for older persons as being a responsibility of other department(s), not that of their department. Certainly, the evidence shows that problems created by the disease are cross-cutting, and need inter-sectoral responses and action. The dissertation has tried to indicate what leadership public health care agencies can take and roles they could play in this regard at the district level.

Indeed, Chapter 6 in the dissertation highlighted the importance of collaborative action between the relevant role players. The policy framework proposed outlines how stakeholders could work together, by each identifying an area of activity where its focus and strengths lies, with the government at the district level playing an overall facilitating and co-ordinating role. Indicators have been proposed to assist stakeholders to measure the realisation of recommendations towards improving older carers' support needs, well-being and quality of life. In addition, the framework identifies barriers to action on the part of the government, such as a general ignorance of older carers' support needs, and how these persons may be targeted in interventions. A key implication of the dissertation and its findings, however, is that a realisation of the policy recommendations will require appropriate budgetary arrangements, and planning to ensure effective implementation and long-term financing of the activities to support older carers.

CHAPTER ONE: THE CONTEXT AND MOTIVATION FOR A STUDY

1.1 STATEMENT OF THE PROBLEM

The effects of HIV and AIDS on households and caregivers, in particular households in which older persons reside and are caregivers to persons living with HIV and AIDS (PLWHA) and orphaned and vulnerable children (OVC), are not well understood. Neither is it adequately known what the support needs of older carers are to help them to cope with the multiple effects of the disease. An investigation is indicated to fill a gap in knowledge in this subject area, and to provide empirical evidence to inform governments and other relevant stakeholders in the development of appropriate policy and programmatic responses to support older caregivers.

It is more than two decades since the HI virus and its disease condition AIDS were identified (Mann, 1989), and awareness of dire effects of the disease started to grow. In 2007, an estimated 33 million people globally were living with HIV (UNAIDS, 2008). The pandemic has resulted in massive suffering and loss of life in many parts of the world, but especially in sub-Saharan Africa and in South Africa in particular. Little more than a tenth of the world's population lives in sub-Saharan Africa, but the region is home to almost 67 per cent of all people living with HIV and AIDS (PLWHA), and has experienced 72 per cent of all AIDS defining deaths (UNAIDS, 2006; UNAIDS, 2008). In 2006, an estimated 2.7 million people in the region were newly infected with the virus, and 2 million adults and children had died of AIDS related conditions (UNAIDS, 2006). Three quarters of females (age 15 years and over) living with HIV worldwide are in the sub-region. In South Africa, almost one in three pregnant women attending public antenatal clinics in 2004 were HIV positive; trends show a gradual increase in HIV prevalence in South African females, albeit with a slight decline in 2006 (Department of Health (South Africa), 2007). Across provinces, the prevalence of HIV is higher, for example, in KwaZulu-Natal (39.1%) than in the Eastern Cape (29.0%) and the Western Cape (15.2%) (Department of Health (South Africa), 2006). Therefore, comparing the three provinces could provide useful information for the development of a policy framework on HIV and AIDS caregiving relevant to South Africa.

Research shows that 90 per cent of care for PLWHA globally is provided at home – in SSA, mainly by older persons. In addition, older persons provide surrogate care to an increasing

number of orphaned and vulnerable children (OVC) – mainly their grandchildren (Ferreira et al., 2001; HelpAge International (HAI), 2003a; World Health Organization (WHO), 2002a, 2000; Uys, 2003; Knodel et al., 2006). Although studies have been conducted in some southern African countries on the effects of HIV and AIDS on older persons, the majority of the studies have been small-scale and localised (Ogden et al., 2005; WHO, 2005; Schatz, 2007; Ferreira et al., 2001). Governments at national, provincial and local, or district levels have thus far neither recognised nor acknowledged the critical role that older persons play in managing HIV and AIDS at a household and community level, nor consulted them or incorporated them in policies and programmes on HIV and AIDS (HAI, 2005a).

Government policies and programmes designed and implemented to mitigate the effects of HIV and AIDS have thus far focused on young people of reproductive age, and have not addressed the information needs of older persons (HAI, 2006a). Older persons are neither targeted in awareness programmes nor supported in their care responsibilities; in short, they are ill-equipped to cope with the burden of care in general (HAI, 2006a; Knodel, 2006; WHO, 2000). It is commonplace for older persons to conceal the presence of the disease in their household, for fear of stigmatisation, discrimination and ostracism in the community; in so doing, such persons and households forego opportunities to receive support from the community. Older persons who care for PLWHA and OVC are often unable, moreover, to continue to engage in income generation activities, to support themselves and their household, because of their advancing age, age discrimination in the workplace, and/or their care responsibilities (Caliandro & Hughes, 1998; Lesar et al., 1995; Steinberg et al., 2002). A general lack of resources, stress related to caregiving, funeral costs when PLWHA die and support for bereaved grandchildren are major concerns to older caregivers (Ferreira et al., 2001; Steinberg et al., 2002; Akintola, 2004).

In recognition of the multiple challenges that older persons in AIDS affected households face, international bodies such as the HelpAge International (HAI, 2003a) have emphasised a need for evidence through research to inform appropriate responses to the effects of the disease on older persons, both as a group at risk of infection and in the crucial role they play as primary carers. Older carers are a valuable care resource to their family, and contribute to development in numerous ways, but their contributions need to be supported and sustained. Unfortunately, policy makers commonly take older persons' contributions for granted. When

older persons are included in strategies to address HIV and AIDS related problems, it is likely to be more by default than design (Ogden et al., 2004).

"Care" provided by older persons in households affected by HIV and AIDS refers to the full range of activities undertaken, including physical care, material support, psychosocial care and support (emotional and spiritual), custodial care (cooking, cleaning, feeding, grooming, helping with toilet needs, etc.), socialisation of young children in their care, health care, and the administration of medications and treatments. In the course of caring for HIV infected adult children and infected grandchildren, older persons are exposed to a risk of contracting the virus and opportunistic infections themselves, due to poor knowledge and understanding on how to care for PLWHA and to protect themselves. Ultimately, the PLWHA for whom they care will die, leaving the carer without support that he or she may have anticipated in old age (WHO, 2002; ASSOM, 2005).

The effects of HIV and AIDS on older persons' households are thus multiple and cumulative, and drain households' resources progressively over time. This situation poses a number of challenges to governments, societies, families and individuals in settings with scarce resources, common or even typical in Africa, including South Africa. Traditional safety nets such as the extended family, that would otherwise have enabled affected families to remain financially stable, are increasingly over stretched (Carballo & Carael, 1988; PANOS, 1990; Taylor et al., 1996). Social capital from which affected households might draw assistance and support, such as family and community members, is diminishing, in part due to AIDS associated mortality, other demographic and social change, and fear of stigma associated with HIV and AIDS (Steinberg et al., 2002). Households with a low level of kin support, or no such support, affected by the disease sometimes face dissolution, as some family members die and others disperse (Barnett & Blakkie, 1992; UN, 2006). Young children may be relocated elsewhere to be cared for by other relatives when their parent(s) die, but research has shown that it is in the children's best interest to grow up in their family home (UN, 2004a). Hence, the support of older carers to enable them to sustain their households and keep them intact is an important consideration as well.

HIV and AIDS policies and programmes need to take account not only of the roles that older persons play and the contributions they make in mitigating the effects of the AIDS epidemic, but also incorporate their multiple socio-economic, health and psychosocial needs in the

design and implementation of appropriate responses. Thus, older carers' contributions and support needs should be integrated in strategies and programmes that can sustain their health and support their well-being, in addition to meeting the needs of other target groups, such as PLWHA and OVC, and other members of the carer's household (UN, 2004). The inclusion of older persons in responses are indicated moreover in terms of universal human rights, provided for, for example, in South Africa's constitution, such as the right of all citizens to equal health and preventive care, and support and treatment (South African Constitution, 1996; UN, 2004a). Yet, their right to information is neither honoured, nor are older persons mentioned in information issued by governments in responses to HIV and AIDS, or in the media, and neither are they targetted in anti-AIDS campaigns (HAI, 2005c).

This dissertation will examine the impact of HIV and AIDS on older persons who care for adult children living with AIDS (PLWHA) and orphaned and vulnerable grandchildren (OVC). A main aim will be to provide empirical evidence to inform appropriate policy development and programme design and implementation to support the needs of older persons who contribute substantially to the care management of the epidemic at community and household levels, and who are rendered vulnerable by effects of the epidemics. It will be argued in the dissertation that the provision of appropriate support to older persons and their households in South Africa may be best co-ordinated and offered through a Primary Health Care (PHC) approach at the district level. The multi-dimensional problems presented by HIV and AIDS require complex approaches to address them. Primary Health Care, with its fundamental principle of a comprehensive approach to address health problems (WHO, 1978), can offer an appropriate framework within which policy and programmatic responses to the needs of older caregivers may be developed, co-ordinated and implemented.

The results of an empirical study, to be conducted as part of the dissertation, will be used to develop a policy framework within a PHC context, as an overall outcome of the study and dissertation. The framework will promote and guide collaboration among stakeholders at the district level: between non-profit organisations (NPOs), community-based organisations (CBOs), faith-based organisations (FBOs), traditional healers, government structures and business, to provide support to older person headed households and families. The study outcomes and the policy framework may be used moreover by stakeholders to encourage lobbying of government ministries to mainstream the support needs of older carers in their programmes and policies, and to close gaps in existing policies. Alternatively, specific

policies and programmes may be developed for this purpose. Recommendations will be made in the dissertation, based on the study outcomes, on how the role and contribution of older persons in the management of the epidemic at the household level may be acknowledged and strengthened, and their caregiving optimised, to better promote, prevent and manage HIV and AIDS in a comprehensive manner at the district level**.**

1.2 EFFORTS TO CONTAIN HIV AND AIDS, AND SUPPORT OLDER CARERS

1.2.1 Policies, programmes and responses

A range of international instruments, such as the Millennium Declaration (UN, 2000) and the subsequent Millennium Development Goals (MDGs) (UN, 2002), developed by global bodies - in this case within the United Nations system, are available, and a large number of Member States, including South Africa, are signatories to the instruments. While governments globally have committed themselves to combating the AIDS pandemic by 2015 (UN, 2001a), much still needs to be done to mitigate the effects of the epidemic on families and households before the goals are achieved. Combating the pandemic is one of the MDG goals, all of which are aimed at development. Older women bear a disproportionate burden of care and support of PLWHA and OVC, and they contribute to development in these ways. However, the burden of care has deleterious consequences for their health and well-being (Ferreira, 2001; WHO, 2002; Akintola, 2004). Thus far, government policies and programmes, especially in South Africa, have done little or nothing to integrate older persons as a care resource and change agents, or agents for development in the fight against the epidemic, or to support their contributions.

The lack of a medical cure for HIV has forced governments globally to emphasise prevention as a response to the pandemic. Only in a few SSA countries has there been strong support for the roll-out of anti-retroviral therapy (ART) – notably Botswana, Malawi, Uganda, Zambia and Zimbabwe, and more recently South Africa (PEPFAR, 2008). Other governments in SSA have tended to rely on prevention programmes, mainly due to the unaffordability of the anti-retroviral drugs, and a lack of infrastructure and suitably qualified personnel to implement therapeutic programmes (AED-USAID, 2003; Esu-Williams, 2003; Akintola, 2004; ASSOM, 2005). The South African government also puts a strong emphasis on prevention, among which are awareness campaigns, the distribution of condoms, the dissemination of

information, voluntary counselling and testing (VCT), the prevention of mother to child transmission (PMTCT), and the treatment of sexually transmitted infections (STIs) (HIV/AIDS and Strategic Plan for South Africa, 2000-2005); older persons have been excluded in all these programmes. These preventive measures alone have not been able to contain the spiralling epidemic in South Africa. Successive Government HIV and Syphilis Ante-Natal Clinic (ANC) surveys indicate that HIV prevalence estimates among the adult population are increasing: from 26.5 per cent in 2002, to 27.9 per cent in 2003, to 29.5 per cent in 2004, to 30.2 per cent in 2005, but with a slight decline, to 29.1 per cent, in 2006 (Makhubalo et al., 2004; DoH, 2007). As a consequence of these high prevalence rates, the under resourced public health system is overstretched, and cannot cope with the increasing number of AIDS related cases (Shisana et al., 2003; De Jong, 2003). In many cases it responds by discharging patients early, to be cared for in the community, mainly by an older relative (Johnson et al., 2002). Unfortunately, when patients have been discharged to be managed at the community level, AIDS treatment has been unsatisfactory, either owing to earlier government contestation of proven efficacy of anti-retroviral (ARV) drugs in containing the spread of the disease or slow rollout of treatment and infrastructure. Nonetheless, the situation is changing, with the appointment of a new health minister in 2008, who supports and facilitates a wide roll-out of ARV treatment within the public health sector. South Africa has shown some improvement in ARV coverage, from 2 per cent in 2004 to 28 per cent in 2008. However, the coverage is still viewed as poor, since only slightly over a quarter of PLWHA who need the treatment get it (*Cape Argus*, 2008:16).

Despite the increasing demands that HIV and AIDS are placing on overstretched public health systems, the burden of care engendered by the epidemics in truth reflects only a fraction of the total number of people in need of care for HIV-related illnesses, as those diagnosed with the virus are a minority of the total number of infected persons (UNAIDS, 2002). Most PLWHA and their caregivers will seek symptomatic relief from pharmacies or treatment from out-patient clinics or a doctor's surgery initially. As the chronic nature of the illness becomes apparent, some will seek treatment from traditional healers (Creswell, 1998; Ankrah, 1991; Osborne, 1996; Peltzer et al., 2005). Caregivers and PLWHA who know or suspect they are infected with the virus may be reluctant moreover to seek care in the public health sector, for a variety of reasons, including a lack of privacy, stigma and fear of depersonalising attitudes of health care providers (Jewkes et al., 1998; Ogden et al., 2004).

Although older persons involved in the management of the epidemics are a crucial resource for the support of PLWHA, they lack appropriate information and skills training, and other resources, such as finance. Thus, while they play a crucial part in a broad continuum of care that enables the referral of PLWHA between different levels of care (Jackson, 2002), public health systems have in effect shifted the responsibility of care to ill-equipped and poorly resourced communities and households, which is an untenable solution to the problem of HIV and AIDS caregiving.

1.2.2 A shift from hospital-based care, to care in the community and households

The United Nations system, bilateral donors, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and governments of affected countries increasingly focus on treatment and care, rather than prevention, as part of their commitment to scaling up the global response to HIV (UNAIDS, 2004a). Public health policy makers have realised that public health systems are unable to manage AIDS-related morbidity, and in the mid 1990s began to consider ways to shift the locus of clinical care from hospitals to health services in the community (Ogden et al., 2004). Initially, hospital based outreach programmes were favoured, whereby hospital staff travelled to patients' homes to provide care. The justification for the hospital initiated home-care models was that, given the limited treatment available in hospitals for many hospitalised AIDS patients, it was neither in the health services' nor the patients' interests for them to be in hospital (Osborne, 1996). Although these home-based programmes were found to be time consuming and expensive, especially in rural areas (Chela, 1995), in most worst affected countries, such as Malawi, South Africa and Uganda, the programmes are still implemented as an alternative to hospital care (Akintola, 2004; ASSOM, 2005; Jackson, 2002; Ogden et al., 2004).

As the public health sector in many SSA countries gradually shifts its provision of care services to PLWHA to communities, arguing that it is in the patients' best interest to be cared for by kin – but in effect absolving itself of these responsibilities, the South African government with the assistance of the European Union (EU) has begun recruiting and funding non-profit organisations (NPOs) to provide home based care (HBC) to affected communities and households (Peltzer et al., n.d). Most of these NPOs provide holistic, or comprehensive care, which addresses all of a patient's needs, and the needs of family carers and OVC to some extent (Jackson, 2002). The majority of the HBC programmes were started

as a response to an increasing need in communities to provide care for PLWHA, who otherwise would not be cared for adequately. They are mainly staffed by local volunteers affiliated to religious groups motivated by compassion (USAID, 2002; UNAIDS, 2000d; Akintola, 2004).

Although the NPOs' main task is the provision of care to PLWHA, some provide information on HIV awareness and prevention, preparation for the care of orphans, income generation opportunities for the PLWHA's family, and promote legal rights relating to property, inheritance and other matters (Ferreira, 2001; Jackson, 2002; WHO, 2002a). Through regular home visits, service providers are in a position to identify households at high risk of impoverishment, and in which children are vulnerable and will be orphaned. Various models of HBC programmes include hospital mobile outreach, AIDS service organisations, faith-based outreach (FBOs), community-based outreach (CBOs), hospices and PLWHA support organisations (Osborne et al., 1997; Jackson & Anderson, 2001; USAID, 2002), which all form a crucial part of the continuum of care between hospital and the community (Van Praag, n.d.; CEDPA, n.d.). However, the NPOs have low coverage, because of resource constraints, such as finance, a lack of skilled personnel and poor infrastructure, such as office or building space (Jackson, 2002).

1.2.3 Low coverage of HIV and AIDS affected households by under resourced non-profit organisations (NPOs)

In general, non-profit organisations (NPOs) are unable to provide clinical care, but may provide basic nursing care, and a range of other care and support services to PLWHA and affected families. Some services help to improve livelihoods, and provide emotional and spiritual support to groups and individuals (Horizons, 2004). Numerous NPOs have limited resources, depend on volunteers, are not linked to broader resources of support and skills, are overstretched, are characterised as "unsystematic and needs based," and cannot cope with the enormity of the challenges presented by the HIV and AIDS epidemics (Blinkhoff, et al., 1999; Jackson, 2002; WHO, 2002b). In South Africa, some non-profit organisations provide various forms of assistance to older carers in AIDS affected households, such as HIV and AIDS education and information, income generating skills training and opportunities, counselling services, information on legal and human rights related matters for the PLWHA, respite care, and advice on application for social grants. However, coverage of all who need to benefit from NPO programmes can only be improved with full government assistance

(Nsutebu, 2001; WHO, 2002c), through an application of PHC principles, such as inter-sectoral collaboration, to address difficulties faced by older persons households affected by HIV and AIDS.

1.3 POPULATION AGEING

Population ageing and older persons are discussed within the context of demographic transition in sub-Saharan Africa and in South Africa in particular. Factors that contribute to population ageing, and the effects of HIV and AIDS, and migratory patterns on older persons are discussed as well.

1.3.1 Older populations and older persons

Population ageing is a consequence of a continuing demographic transition of unprecedented declines in fertility levels, and lower levels of mortality and increased migration. In the process, the proportion of children and youth in a population shrinks and the proportion of older persons expands (Stloukal, 2001; Marcoux, 2001; Udjo, nd; UNFPA, 2002). Most developed countries began to witness major reductions in the size of their population, first in death rates and subsequently in birth rates, when they started to fail to achieve replacement levels, more than a century ago (UN, 2007a). As the proportion of children in these populations declined, the population structure began to age (UNFPA, 2002). By 2050, the number of older persons in the world will for the first time exceed the number of young people, and most of these persons will live in developing regions such as in Africa (UN, 2001b; UNFPA, 2002) (see Table 1.1).

Different factors contribute to the rapidity of the ageing process in the African continent, predominant among which is a reduction in fertility and, to an extent, AIDS related mortality (UNDP, 2007, Udjo, 2006). The United States of America Census Bureau (USCB, 2005) estimates that the absolute number of people age 50 years and over in sub-Saharan Africa will double from 74 million in 2005 to over 140 million in 2030. However, in contrast to population ageing in the developed world, where the transition occurred slowly and in a well resourced environment, the demographic process in sub-Saharan Africa is occurring rapidly, and in an environment with high levels of poverty and communicable disease, such as HIV and AIDS (Kent & Haub, 2005).

Table 1.1: Size and distribution of the population aged 60 years and over, worldwide, shown separately for more developed countries and less developed countries, 1950–2050

Region	More developed countries		Less developed countries		World
Year	millions	%	Millions	%	Millions
1950	95	46	110	54	205
1970	147	47	165	53	312
2000	232	38	374	62	606
2020	317	31	707	69	1. 024
2050	395	20	1. 569	80	1. 964

Source: Adapted from United Nations (2001) for the medium variant.

Old age is defined variously by different nations and in different regions, influenced to an extent by demographic trends, such as high or low life expectancy, and social, cultural and political factors. The lower cut-off age used for "older persons" by the United Nations is 60 years; this cut-off, rather than the earlier higher cut-off age of 65 years, is now used globally (UNPFA, 2002a). However, in sub-Saharan Africa, chronological age is often a poor yardstick to measure age. Rather, life experience, knowledge of important events and physical appearance (e.g. greying hair) are considered more indicative in denoting an individual as "old" (HAI, 2002b; Nhongo, 2004).

Globally, the older population is growing at a rate of 2.6 per cent per year, faster than the rate of 1.1 percent for the world population as a whole. This trend is expected to continue until 2050. The population aged 60 years and over will moreover grow more rapidly than any other age group (UN, 2007a). In addition, the proportion of older women is expected to increase

disproportionately to that of older men in the coming decades, due to significantly higher survival rates of females at every age (UNFPA, 2002a; UN, 2007a). Therefore, by implication, issues of health provision, housing and social protection will be critical for their well-being**.**

With regard to the SSA region, life expectancy at birth is currently 43 years. However, life expectancy at age 60 in the sub-region is 18.5 years for females and 14.2 years for males (UN, 2007a). In South Africa, life expectancy at birth is 43.8 years for females and 44.2 years for males. At age 60, females can expect to live another 22 years and males, another 17.1 years (UN, 2007a). The relative longevity of older individuals in South Africa, compared to other SSA countries, is thus evident. In the age group 80 years and over, life expectancy for females is 7.4 years and for males 6.4 years for the period 2005-2010 (UN, 2007a). Certainly, AIDS related mortality has reduced life expectancy at birth, but survivors to age 60 may still enjoy longevity.

1.3.1.1 *Older persons in South Africa*

In 2008, South Africa's population aged 60 years and over numbered 3.5 million (Statistics South Africa, 2008). The racial composition of the older population was black Africans 64.2 %, whites 24.3 %, coloureds 8.3 % and Indians/Asians 3.2 %. The ratio of older males to older females was 0.6 (StatsSA, 2008). In the Eastern Cape Province, in 2006, blacks constituted 87.6 % of the older population, and in KwaZulu-Natal 84.4 % and the Western Cape 27.3% (StatsSA, 2006). Table 1.2 below shows the current distribution of older persons by five-year age category, sex and population group in the three provinces in which the empirical study will be conducted. The figures show a decreasing trend in the number of older persons in each age category, from the youngest to the oldest category (above 50 years). Nonetheless, the size of the oldest age group (persons age 80 years and over), especially women, is notably large. These persons may be expected to suffer some physical and/or mental impairment, and co-morbidities, and will require care and support. Thus, the South African government will need to plan to meet the care needs of this age segment through service provision and resource allocation.

Table 1.2: Provincial distribution of persons (age 50+)(1000s), in three provinces in South Africa, by five-year age categories and sex

Age group (years)	Eastern Cape		KwaZulu-Natal		Western Cape		Total		
	Male	Female	Male	Female	Male	Female	Male	Female	Total
50-54	109900	146600	150200	183000	98100	106200	358200	435800	794000
55-59	89200	120900	124800	159200	78800	88800	292800	368900	661700
60-64	83700	111000	106200	135400	71100	78600	261000	325000	586000
65-69	75400	109700	77600	106900	54000	55900	207000	272500	479500
70-74	55500	78200	48000	73200	37800	39200	141300	190600	331900
75-79	32900	47300	28500	48300	20500	22900	81900	118500	200400
80+	23600	40000	20300	37700	14800	23100	58700	100800	159500
Total	470200	653700	555600	743700	375100	414700	1400900	1812100	3213000

Source: Adapted from mid-year population estimates, Statistics South Africa, 2006. (All numbers in this and subsequent population related tables have been rounded off to the nearest thousand, which may lead to small differences in the totals by age and sex.)

Although an expanding older population signifies longevity, which should be viewed as an achievement and not a problem. However, a major challenge in many SSA countries, in particular, is that many older women are faced with the challenges of HIV and AIDS caregiving, late-life parenting, the lack of a spouse, the effects of changing kinship support systems, and a lack of formal, or government support.

Table 1.3 shows the distribution of older persons in urban areas and non-urban areas in the three provinces in which the empirical investigation will be conducted. In terms of absolute numbers, the highest number of older persons resides in KwaZulu-Natal, with an almost equal distribution in urban and non-urban areas. The Eastern Cape Province has the highest proportion of older persons living in non-urban areas, while the Western Cape Province has the highest proportion living in urban areas.

1.3.2 HIV and AIDS, and population ageing in sub-Saharan Africa

The HIV and AIDS epidemics in sub-Saharan Africa continue to change the age profile of this highly affected sub-region (UNPFA, 2002a). It is estimated that by 2025, the size of the population of the 38 worst affected countries, including South Africa, will be at least 156 million smaller than it would have been in the absence of AIDS, and that 58 million children will not have been born because of the early deaths of women of reproductive age (UN, 2006) (see Table 1.4). The epidemics will therefore affect population growth negatively in the highly affected countries.

South Africa is the most developed country in Africa in terms of economic development. However, although it has a middle-income economy, it has a large third world section of the population, virtually mired in poverty. Nonetheless, it has relatively well developed infrastructure – roads, telecommunication and electricity network – and a developed public health system (see Callaghy, 1993; Therkildsen & Semboja, 1995; Clapham, 1996). It also has the highest AIDS prevalence, after Swaziland (see UNAIDS, 2004a/06).

Table 1.3. Proportional distribution of persons (age 50+) in three provinces of South Africa, by urban area and non-urban area (numbers and percentages)

Eastern Cape			KwaZulu-Natal			Western Cape			Total
Urban	Non-urban	Total	Urban	Non-urban	Total	Urban	Non-urban	Total	
377 238	601 158	978 396	596 287	629 942	1 226 229	626 579	58 883	688 462	**2893087**
38.6%									
	61.4%		48.6%	51.4%		91.0%	9.0%		

Source: Adapted from the South African Population Census 2001, Statistics South Africa.

.

Table 1.4: Projected effects of HIV and AIDS associated mortality on population size in 38 worst affected sub-Saharan African countries (millions) and population growth rates (percentages), 1995-2025

	Population size (millions)			Annual population growth (percentage)	
	1995	2015	2025	1995-2015	2015-2025
Without AIDS	539	914	1139	2.6	2.2
With AIDS	533	823	983	2.2	1.8
Absolute difference	6	91	91	0.5	0.4
Percentage difference	1	10	14	-	-

Source: UN Population Division: The 2002 revision (UN, 2002).

In South Africa, AIDS associated mortality is starting to affect population ageing: the impact of the epidemic is producing a negative growth rate among the youth compared to the older population (Udjo, 2006). Actuarial Society of South Africa (ASSA) estimates indicate that mortality levels in older persons have stayed fairly constant over the past two decades and will remain so over the next two decades; hence, AIDS related mortality is not yet affecting these levels, to the extent that it is contributing to mortality in the young age groups (ASSA, 2004). However, increased AIDS related mortality levels in infants, children and young adults are having a temporary accelerative effect on population ageing (Joubert et al., 2005).

More important for this dissertation are the consequences of HIV and AIDS associated morbidity and mortality which erode the support base for older persons and bring added caregiving responsibilities to ill-equipped older carers (Ferreira et al., 2001; Johnson et al., 2002; WHO, 2002a). Thus far, the effects and erosion of the support base have received little attention, in either the media or discourse on demographic effects of the diseases on population groups, compared to the attention given to orphans and the youth (Barnett & Whiteside, 2002; UN, 2005). This dissertation thus aims to provide evidence of the multiple losses experienced by affected older persons, which includes the erosion of a support base.

However, research shows that although the prevalence rate of HIV infection in older populations has not been established routinely, older people are nevertheless at risk of infection with the virus (UNAIDS, 2007). Before anti-retroviral therapy (ART) became

widely available, an estimated 6 per cent of the total HIV case load in sub-Saharan Africa was in the population aged 50 years and over (Knodel et al., 2003). Data from the Swaziland Demographic and Health Survey (DHS) (CSO, 2008) indicate an HIV prevalence in the population aged 50 years and over of 14.2 per cent (11.7 % for women, 17.9 % for men). Despite the evidence of older persons' susceptibility to HIV infection, they are overlooked by governments in interventions designed to halt the spread of the disease.

1.3.3 Migration and ageing

In sub-Saharan Africa, migration and the variable circumstances surrounding population movement and disruptions, such as vicious cycles of conflict, poverty and more recently AIDS, contribute to population ageing, especially in rural areas. In South Africa, migration patterns are characterised by a rural-to-urban flow of young adults (especially young African men) who move to cities for better economic and education opportunities (Kok & Collinson, 2006). A consequence of rural-to-urban migration is a "natural increase" of urban populations and a decline in rural populations, primarily due to out-migration and a decline in fertility rates in rural areas. In addition, less out-migration of older persons contributes to the ageing of rural populations (Garenne et al., 2006; Kok & Collinson, 2006; Marcoux, 2001; Skeldon, 1999; Stloukal, 2001).

An exodus of young adults from rural areas translates into hardships for older persons left behind in a poorly resourced rural area, through a loss of able bodied younger persons to help till lands, grow crops and tend livestock (Stloukal, 2001; UN, 2001b; Fouad, 2004; Mba, 2004). When older persons left behind find they can no longer cope on their own, they may follow their kin to an urban area, but where they may experience difficulty in joining kin, and residing in an unfamiliar and often disorganised environment. As a consequence, they may return to their area of origin, or become circular migrants, residing for periods alternately in an urban home and a rural homestead (Kimuna, 2004; Nxusani, 2004).

Young adults too may migrate circularly, which carries a risk that they will become infected with the HI virus in an urban centre and then infect residents of a rural area (UN, 2005). Moreover, when young migrants in an urban area become ill with an AIDS related condition, they tend to return to their rural family home, to be cared for by family, typically an elderly mother, where they will live until they die (Lurie et al., 1997; Knodel, et al. 2002; UNAIDS,

2003; Clark et al., 2005; Garenne et al., 2006). Hence, not only do older persons in rural areas have particular vulnerabilities as a result of a loss of a migrant kin, they must often assume additional livelihood and caregiving responsibilities at a time when they themselves may be becoming dependent and in need of care and support.

1.4 CHANGING FAMILY STRUCTURES AND RELATIONSHIPS

1.4.1 Family structures

The concept of "family" has been defined variously in different societies and cultures (Nzimande, 1996). Contemporary family forms are more fluid than previously, or compared to traditional kin structures in SSA countries, and may be shaped differently in different social, cultural, legal and political contexts. Nonetheless, for the purpose of this dessertation, and a policy intervention to be developed later, the concept of family is defined operationally as a group of kin who co-reside in a house, but other family members may live elsewhere. One of the family members in the household assumes (or is assigned) the role of head of the household. Kin who live elsewhere constitute the extended family (of the co-resident family members). A variety of contemporary family forms in SSA countries are discussed below.

1.4.2 Changes in family structures and relationships

In sub-Saharan Africa, family structures are changing due to a variety of demographic trends, and economic and social factors. Migration is one such trend and factor. As young adults move from a rural area to an urban centre, and establish themselves at the area of destination, the family structure may change from a traditional extended family structure, typical at the area of origin and still predominant in rural areas, to a nuclear family form, increasingly common in urban centres (Jones, 1996). Other evolving, and increasingly common, family forms include skip-generation families where no middle generation family member is present, either because they live elsewhere or have died, increasingly as a result of AIDS (WHO, 2002a). Family members may be widely dispersed moreover: some may live in an urban area, while others remain at an ancestral site in a rural area. The structure, functions and internal relationships of a family are therefore affected by such mobility patterns (UN, 2005). In South Africa it has been noted that unemployed and/or sick adult children may regroup in their parents' home, with the grandchildren, to be cared for by a grandparent (Moller & Ferreira, 2003). Finally, child headed families, where no adult is present and both parents

have presumably died – typically from an AIDS related illness, are increasingly common (Giese et al., 2003; Lang, 2005).

The effects of AIDS, such as associated illness, or the death of a young father or mother, or both, mean that children may need to be relocated to be cared by other family members elsewhere, in most cases by grandparents, especially a grandmother (WHO, 2002a; UN, 2005). Hence, some families, or households will experience an increase in the number of co-resident young children rendered vulnerable or orphaned by AIDS.

Changes in family structures may alter relationships between family members. In skip-generation households, the generation gap between grandparents and grandchildren may contribute to strained relationships, especially where grandchildren are disobedient and perceived to be disrespecful (HAI, 2003a; HAI, 2005b). Several trends and factors in the SSA sub-region thus contribute to changes in family structures, and by implication to changes in family relationships. Such changes typically result in a reversal of roles for older persons, as they become care providers, no longer care recipients, which latter role they may indeed have anticipated in old age (WHO, 2002).

1.4.3 The burden of caregiving in older person households affected by HIV and AIDS

The burden of caregiving in households affected by HIV and AIDS in South Africa needs to be investigated and understood in terms of a clear role distinction between the sexes in traditional African society. Historically and traditionally, older women have been caregivers: to a spouse and other household members, but especially to grandchildren when the children's mother is sick or absent. Caregiving roles include cleaning the hut, cooking and general maintenance of the home, and caring for the children, the elderly and the sick. Men in African households have historically and traditionally functioned as sole breadwinners, disciplinarians and family heads (Eden, 1991). Men's relationship to their children has thus tended to be authoritarian and disciplinarian, while women's relationship has been one of caring and nurturing. Clearly, caregiving has been gendered in nature and has been women's responsibility (Ferreira & Kalula, 2009). The roles and responsibilities of women in this regard will be considered from a feminist theoretical perspective in chapter 2.

The nature of caregiving for older women in African society has changed somewhat in the era of HIV and AIDS. Now, older women increasingly take care of adult children with AIDS

related illness, and grandchildren with the disease, or orphaned or rendered vulnerable by it (UNICEF, 2004, 1999; Ferreira et .al 2001; WHO, 2002). The resulting burden of care may indeed be heavy, and negatively influence the health and well-being of older women, and limit opportunities for them for social interaction (WHO, 2002).

In this dissertation "household" is defined as a configuration of persons of two or more generations, typically family members, who co-reside in a dwelling. The definition recognises that the household occupies a particular space (a physical structure, or dwelling), and household members share resources. In SSA countries, as has been noted, household configurations are increasingly reshaped by the effects of various demographic trends and social and economic change, especially effects of HIV and AIDS and migration of younger kin. Moreover, older women in affected households increasingly become primary care providers as a result of these changes. As primary carers, they carry the burden of responsibility and care, which is multifaceted. Not only do they care for PLWHA and grandchildren, but must cope with their own deteriorating health, often exacerbated by the stress of caregiving and responsibility (HAI, 2002b). Older persons commonly suffer from chronic disorders such as hypertension, musculoskeletal conditions, respiratory illness and mental health disorders (Ferreira et al., 2001; Akintola, 2004; Joubert & Bradshaw, 2004). Numerous older persons have limited knowledge about the HI virus and its transmission (WHO, 2002a; HAI, 2005c), which then puts them at risk of infection with the virus (WHO, 2002a).

The burden of care has direct and indirect costs on older carers. Direct costs include financial, material and time costs, increased expenditure needs, food insecurity, poverty, health costs and psychological costs. Indirect costs include changing roles, social isolation and stigma, emotional suffering and grief (Johnson et al., 2002; Ogden et al., 2004; Hansen, 1994 in Ogden et al., 2004; Sauerborn et al., 1996; Bachman & Booysen, 2003). An assessment of the financial needs of the caregivers will be undertaken.

1.5 A PUBLIC HEALTH RESPONSE TO SUPPORT OLDER CARERS

By definition, public health is not about individual patients but focuses on disease, and health conditions and problems affecting people collectively, or the public. Thus, public health care aims to provide maximum health benefits to the largest number of people. A public health

approach to a health problem is interdisciplinary, intersectoral and science-based. It draws upon knowledge from multiple disciplines, including Medicine, Epidemiology, Criminology, Sociology, Psychology, Education and Economics (Mercy, 1993; WHO, 2004b). Its interdisciplinarity has enabled the public health field to be innovative and responsive to a wide range of illnesses, injuries, diseases conditions, such as HIV and AIDS epidemics.

Since 1994, the South African government has adopted Primary Health Care (PHC), that is health care provided at the primary level in a three tiered health care system, as a vehicle to deliver public health care services. It has used the District Health System as an implementation strategy to ensure that health services are accessible and responsive to the needs of various communities (Pillay et al., 1998). The need to address AIDS has been declared a public health priority and is a Presidential Lead Project (Abdool-Karim, 1995). Among the principles that PHC promotes is a multisectoral approach, or intersectoral collaboration (ISC) to address community and family health care needs (WHO, 1978). Given the multifaceted and complex (health, psychological, social, economic, and developmental) issues presented by the HIV and AIDS epidemic, Primary Health Care, with its comprehensive and intersectoral approach to addressing health problems and the well-being of communities, may be the most appropriate intervention to address challenges faced by households affected by HIV and AIDS (UNAIDS, 2002; WHO, 2002).

Intersectoral collaboration is a process of interaction in which two or more parties identify mutual interests and agree to work together towards a common goal (Challis et al., 1994). The term ISC is used to refer to collaboration between government departments. However, within a PHC context it entails collaboration between government, business, communities and other significant role players in society, to link health care provision to other aspects of socio-economic development that are closely related to health (Pillay et al., 2001; WHO, 2004b). The PHC approach has not been applied in South Africa at the district level to address the multiple problems presented by HIV and AIDS to older person headed households.

A critical element of ISC is intersectoral action. Government, business and strong community participation are essential to all aspects of a comprehensive approach to HIV and AIDS: prevention, care, support and research (World Health Organization, 2004c). UNAIDS has established GIPA, the Greater Involvement of People with HIV and AIDS and their families

(UNAIDS, 1999), which among other activities advocates the promotion and involvement in national responses of people affected by the epidemic such as older caregivers.

Bringing together affected persons and communities in a comprehensive care approach to health problems needs well thought-out models. How, for example, may older persons be equipped and involved in anti-HIV and AIDS strategies? The success of involving older persons in efforts to control or manage HIV and AIDS may have important implications for the broader public health agenda. Indeed, the need for community involvement in the roll out of anti-retroviral therapy, counselling, supervision, monitoring treatment of side effects and support represents an opportunity to build skills and catalyse collaboration between communities, health care providers and public health work, and to help strengthen health systems across the board (WHO, 2002; WHO, 2004c). Research literature on older persons' role in mitigating the effects of HIV and AIDS in countries such as Zimbabwe, Botswana and Mozambique, and on health care support and the empowerment of older women in AIDS prevention in Botswana, found that when previously marginalised grandmothers were provided with knowledge and skills, they became an important and effective resource in the prevention of the spread of the disease and mitigation of its effects (Tlou, 1996; HAI, 2003a; WHO, 2002; Aubel, 2005).

1.5.1 Models to involve older persons in health care service delivery

Although not widely recognised, older persons already play an important role in the "continuum of care strategy" promoted by WHO to address HIV and AIDS at all levels of care (PAHO/WHO, 2000, CEDA, n.d). The strategy involves caregiving at home and in the community, and care at primary, secondary and tertiary levels. Each care level is a service point on a continuum of care for PLWHA and together the points constitute a comprehensive care network. Older caregivers are a vital link in the referral chain between hospitals, clinics, NPOs, CBOs, FBOs and households, where PLWHA are ultimately cared for 24 hours a day, seven days a week. In some developing countries in Africa, Asia and South America, models to involve older persons in the delivery of health services at district level have been tested and applied successfully. The generic grandmother-inclusive methodology model, for example, has five key steps: i) Rapid assessment of grandmothers' role and influence in the household and community related to the issues of interest; ii) public recognition of grandmothers' role in promoting health and development of families and communities; iii)

participatory communication/education activities that engage grandmother networks first, and other community members, second, in discussion of both traditional and modern practices; iv) strengthening the capacity of grandmothers, in families and in the community; and v) ongoing monitoring and documentation for learning (World Bank, 2006; HAI, 2006a).

When this methodology was assessed in both Africa (Senegal) and Asia (Laos), it was found that older persons, including illiterates, are capable of learning new things when the pedagogical approach used is based on respect and dialogue. Hence, older persons are open to combining "new" practices with "old" ones, even when this means abandoning certain traditions (World Bank, 2006). Furthermore, the proportion of older persons who advised mothers with young children to continue breastfeeding during diarrhoea increased from 73 per cent at baseline to 90 per cent at endline (Aubel et al., 1997). In South America (La Paz), older persons were trained in monitoring the implementation of free health care for older people with no health insurance. The results were improved services such as reduced waiting times for older persons at local clinics and the assignment of medical staff with training in older persons' health issues (HAI, 2006b). In a nutrition education project in Senegal, improvements were noted in all indicators relating to grandmothers' advice to younger women and to their own practices with young children (Aubel et al., 2004).

Such evidence and experiences illustrate how government PHC programme developers and planners can put PHC principles into practice, such as community involvement in the delivery of health services in the community and to families. Older persons thus are an important and readily available resource in most communities hard hit by the HIV and AIDS epidemic in South Africa. However, they need support in a number of areas, one being to ensure access to health care – in order to prolong and improve their quality of life, and sustain their contributions, and enable them to participate meaningfully in training and development programmes. Older persons have a right to participate in health care delivery within the district in which they reside. The district health system makes provision for community participation through clinic or community health centre committees (Pillay et al., 1998). Clinic committees are thus a mechanism through which older persons can be drawn into mainstream PHC delivery.

1.6 A RATIONALE FOR THE STUDY

A rationale for the study of older carers' support needs is outlined in three parts: 1) The relevance of the study to society, in terms of the evidence it will yield of the central and crucial role played by older persons in SSA countries and South Africa in the care management of the HIV and AIDS epidemics, and a need to support older carers and their households comprehensively. 2) The relevance of the study to the PHC system, in terms of argumentation in the dissertation for co-ordinated responses to older carers' situations and needs at a district level. The study will have relevance for public health care delivery at community and household levels, as well as for appropriate policy development and implementation. 3) The relevance of the study outcomes in terms of the contribution it will make to knowledge and methodology in the subject area. The parts are elaborated below.

1.6.1 Relevance to society

The relevance of the study to society is two fold: 1) International bodies such as UNAIDS and WHO that work to mitigate the effects of HIV and AIDS tend to focus on people of reproductive age (15-49 years), and children rendered vulnerable or orphaned (OVC) by AIDS. Although older persons are increasingly at risk of infection with the HI virus, they are not targeted in anti-AIDS campaigns, nor do they enter routine surveillance systems, and are neither included in national prevalence estimates, based on ante-natal clinic (ANC) estimates (UNICEF & USAIDS, 2002; HAI, 2005c; Shisana et al., 2005). 2) Although some recognition has been given to older persons' role as care providers to PLWHA and OVC (UN, 2002; UNAIDS, 2004b), they remain unsupported and have largely been overlooked in AIDS policy and programmatic responses (HAI, 2005c).

This dissertation will seek to contribute to knowledge on the complex effects of the epidemics on older caregivers and their households, within SSA settings, and the contributions they make to mitigate the effects and sustain the well-being of their family and community. The study will yield empirical evidence to promote and inform dialogue among relevant role players, including governments. A policy framework will be developed within the dissertation to guide decision makers and other stakeholders in the design and implementation of responses to the caregivers' support needs, to sustain their contributions to family, community and society.

1.6.2 Relevance to public health care

No public health care responses to the HIV and AIDS epidemic in South Africa support affected or infected older persons specifically, despite growing evidence of their being at the forefront of the management of effects of the epidemics at a household level (Ferreira et al., 2001; Bachman & Booysen, 2002; Makiwane et al., 2004). The relevance of the study and dissertation to PHC delivery will lie mainly in the understanding it will provide of the circumstances under which older persons care for PLWHA and OVC. The information the study engenders will be available to inform decision makers, and programme planners and providers on how to respond appropriately to older carers' support needs and a need to protect themselves against infection with the virus at a district level. The empirical evidence the study generates will inform the development of a policy framework to guide PHC, or district management in the design and implementation of appropriate policy and programmes. Recommendations of the study will offer guidelines additionally on how older caregivers may be recruited, trained, supported and integrated into a broad PHC response.

It will be argued in the dissertation that access barriers to PHC experienced by older caregivers must be removed, and public health strategies should help older carers – and their charges – to cope with the burden of care by sustaining or improving the health of the primary caregivers (UN, 2004c). Strengthening intergenerational solidarity and well-being should be central in enabling affected families to cope, and minimising the burden on the over-stretched PHC system (Horizons, 2006). Hence, the relevance the dissertation for public health care will lie chiefly in the information that it provides to inform the development of a policy framework for employment at a district level, which may help to facilitate and co-ordinate the activities of government officials and various other role players in supporting affected older persons' households. The information will serve moreover to inform health care and HIV and AIDS policy processes of older persons' health care needs in general.

1.6.3 Relevance to research methodology

The study will contribute to knowledge in the problem area, specifically through the research design and the research methods employed in the empirical study; in turn, the study will contribute to the design of innovative research approaches and research methodology for other investigations in this subject area. Specifically, and innovatively, the study will i) use a mixed-methods design; ii) gather both qualitative and quantitative data – through a field

survey, follow-up in-depth interviews and case studies, and interviews with key informants; and iii) triangulate (Poundstone et al., 2004; Green et al., 1989) results of analyses of the multiple data sets. The majority of studies in the subject area to date have been of a qualitative type, small-scale and conducted in single settings, thus limiting comparisons between settings and capture of the magnitude of the problem of HIV and AIDS caregiving.

1.7 OBJECTIVES OF THE STUDY

Against the above background and the rationale outlined for the study, objectives of the study are stated as follows**:**

i) To determine the nature and burden of care on older caregivers in households affected by HIV/AIDS in three provinces of South Africa;

ii) To identify the financial, physical, social, emotional and health care needs of older caregivers, and factors facilitating and hindering caregiving in urban and non-urban areas of the provinces;

iii) To assess the caregivers' knowledge of HIV/AIDS;

iv) To review and evaluate current policy responses to the support needs of older persons affected by HIV/AIDS;

v) To assess how various role players at the district level can support older person households affected by HIV/AIDS;

vi) To provide evidence for policy makers and planners, to inform the design and implementation of appropriate policies, strategies and programmes;

vii) To develop a policy framework to forge collaboration among role players at a district level;

viii) To develop (potential) indicators to measure and monitor the implementation and achievement of key areas of the framework;

ix) To make recommendations for policy, programme review and reform, or new policy development and programme design, and implementation, for district management regarding the support needs of older persons in households affected by HIV/AIDS.

1.8 RESEARCHER'S POSITIONALITY

The researcher's positionality in the study is as follows: Prior to the study, he was employed at the Human Sciences Research Council (HSRC), where he gained considerable experience in research problem formulation, research methodology, and the management of research data and the dissemination of research outcomes, as well as conducting research on HIV and AIDS affected populations. Prior to working at the HSRC, he was employed as a researcher and development worker in low socio-economic communities in the Western Cape Province. During the study, the researcher left the employ of the HSRC and since then has been employed as a senior researcher in the Institute of Ageing in Africa at the University of Cape Town. The researcher has therefore worked extensively in a research environment, and latterly specifically in the areas of ageing, older persons, HIV and AIDS, and health and social care. Field notes kept by him from projects conducted in these areas over the years provided him with a rich source of information regarding older persons and caregiving in general. These notes would be helpful to form a broad picture of the context of the carers' situations, and to elaborate on analysis of the qualitative data to be collected and in writing up the dissertation. Moreover, his linguistic and cultural commonality, and first-hand observation of older carers in the study population enabled him to seek to understand older carers' situations acutely and sensitively.

The researcher's involvement in the dissertation and study will entail the conceptualisation of the study; a review or related literature and policy; the development of tools to gather data (i.e. a survey questionnaire, case study and key informant interview schedules, information/consent forms and resource pamphlets); recruitment and training of fieldworkers and field supervisors in each province; management of the fieldwork; negotiation with participating NPOs and community leaders to gain access to the study sites and participants; conducting of qualitative studies; capture of the data; statistical and content analysis, and triangulation of different datasets; interpretation of the results; and the construction of a policy framework.

1.9 OUTLINE OF THE DISSERTATION

The dissertation is organised in seven chapters as follows**:**

Chapter 1 gives background, and states the problem for investigation and a rationale for the study. An argument is made out that while older carers contribute substantially to the care management of the HIV and AIDS epidemics in sub-Saharan Africa, their contributions and capacity need to be integrated in mainstream responses to effects of the epidemics, and the carers need to be supported, in this case at the district level.

Chapter 2 reviews literature on the effects of HIV and AIDS on older persons; the contributions that older carers make to mitigate the effects and the challenges they face; and the epidemics as a public health problem. Issues examined include problems relating to orphanhood – due to AIDS mortality, such as psychological development, schooling and health of OVC, challenges posed by stigma and discrimination associated with HIV and AIDS directed at older persons, and related stress and difficulties associated with caregiving.

Chapter 3 reviews international instruments and relevant national policies, strategies and programmes and community responses, in terms of their inclusiveness and responsiveness to the support needs of older persons affected by HIV and AIDS. Policies, programmes and legislation in South Africa in this regard are examined specifically. Community based care models and programmes within a PHC context are evaluated to assess their supportiveness of affected older person households. Gaps in policy are identified, as is a need for a policy framework for the development and implementation of appropriate responses within a PHC system elaborated.

Chapter 4 describes the research design employed in the study: a mixed-methods design that incorporates quantitative and qualitative techniques – specifically, a field survey, follow-up unstructured (qualitative) interviews (case studies), and interviews with key informants. Planned triangulation of the results of analyses of the several datasets is described.

Chapter 5 presents the results of analyses of the survey data, the unstructured interview data and the case studies, and the key informant interview data, in three parts. The results of the analyses are then triangulated in a fourth part, and the study findings discussed broadly.

Chapter 6 develops a policy framework for decision makers and other stakeholders, for employment to inform policy and programmatic review and reform, towards the provision of support of older caregivers at the district level. The chapter draws on the outcomes of the literature and policy reviews in Chapters 2 and 3, and the results of the survey and triangulation of the findings in Chapter 5. The framework elaborates nine key desired outcomes to be accomplished to meet the support needs of older caregivers, and benefit older persons in general, at the district level.

Chapter 7 draws conclusions of the dissertation, evaluates the study and dissertation, and makes recommendations for strengthened policy and programmatic responses to older carers' support needs in sub-Saharan Africa and South Africa specifically.

CHAPTER TWO: REVIEW OF THE RELEVANT LITERATURE

2.1 INTRODUCTION AND BACKGROUND

Literature relevant to the problem for investigation is reviewed in chapter 2. The chapter is divided in four parts: Part A examines the situation of older persons who become carers to persons living with HIV and AIDS (PLWHA) and orphaned and vulnerable children (OVC) in sub-Saharan African (SSA) and South African settings. Part B examines informal caregiving at the household level and the nature and challenges of the caregiving. Part C examines non-formal care provided by non-profit service organisations (NPOs). Part D investigates formal care provided by the government through social security and health care services, and considers opportunities for Primary Health Care (PHC) to render support to older carers, which include integrating them in service and intervention programmes at a district level; harnessing their energy, skills and other resources; and supporting the carers in order to sustain their contributions to the care management of the epidemic. The state of knowledge in the subject area, as embodied in the literature, is evaluated throughout the chapter. Gaps in knowledge are identified at the end of the chapter.

Theoretical perspectives employed in the dissertation are outlined briefly in Section 2.2 first.

2.2 THEORETICAL PERSPECTIVES

Several theoretical perspectives were considered as being appropriate for employment in the dissertation, among which were Family stress theory (Hill, 1949), Marxist theory (Curtis, 1996) and Development theory (Kasternbaum, 1993). However, two other theoretical approaches were selected for this purpose: Social exchange theory and Feminist theory. The theoretical perspectives are employed in the dissertation to develop analytical and explanatory frameworks, as a lens through which to examine and understand caregiving by older persons at the household level.

2.2.1 Social exchange theory

Social exchange theory was developed by George Homans (1958) who employed it to study and explain motivations for behaviour relating to reciprocity: specifically, the balance and structure of social exchanges in micro-economic undertakings. Social exchange theory differs

from classical micro-economic theory in that long-term relationships are of interest, whereas micro-economic theories were developed on an assumption that exchanges take place between people who do not know one another (Molm, 2001). Social exchange theory can be applied in a range of disciplines, but in all instances the driving force is that of actors exchanging resources – tangible and non-tangible – through or within a social relationship (Homans, 1961). Between household members, for example, tasks become exchangeable resources, as do financial arrangements, or wealth flow patterns. The theory attempts to account thus for exchange behaviour between individuals, or within dyads (Emerson, 1976; Bumagin & Hirn, 2001). Such behaviour may differ between individuals of different ages, because of shifts in roles, skills and resources over time and that accompany ageing.

The relevance of the theory for the construction of an analytical and explanatory framework in the dissertation is as follows**.** Exchanges between actors within households (i.e. caregivers, PLWHA and OVC) are both tangible (monetary, food, shelter, etc.) and non-tangible (co-operation; availability, respect, companionship, etc.). The PLWHA and OVC may therefore co-operate and/or show respect, for example, to an older caregiver in return for care (accommodation, food, clothing, money, medication, emotional comfort, etc.). However, exchanges between actors may not be equal, and may result in one actor (e.g. a. caregiver with more resources than the person being cared for) being "in control of" the exchange relationship. Exchange theorists equate such control with power, since the caregiver will have more to give than the care recipient – at that stage. Although there is an element of reciprocity between the actors, older persons tend not to put an emphasis on reciprocity, especially when the beneficiary of the resources is a family member (Stoller, 1985). Reciprocity may indeed be postponed until such time as the carer is him-/herself in need of care. With advancing age, older persons may depend increasingly on their children, and to some extent on their grandchildren – for whom they cared – for support.

It is accepted that numerous older persons provide critical support to their children and grandchildren (Walker, Martins & Jones, 1992), especially in multi-generational households affected by HIV and AIDS. In such households there will be gains and losses in social exchanges for older caregivers – because of the nature of the effects of HIV and AIDS and the demands of caregiving. Hence, while PLWHA and OVC will benefit from an older person's caregiving, the older person him-/herself may forego privacy, energy, social contact

and income generating opportunities, and the carer's health may deteriorate; losses therefore outweigh gains. The older caregiver is likely moreover to experience stress due to a variety of factors, such as overcrowding of the residence, caregiving responsibilities, concern and anxiety (Bumagin & Hirn, 2001; Mckenry & Price, 1994).

Older caregivers by definition assume the role of caregiving at an advanced age, and some may be needy and/or disabled. Despite frailties, the evidence shows that they nonetheless want to protect and care for their offspring, whom they view as their responsibility, do not see any alternative than to care for them themselves (Bumagin & Hirn, 2001). In better times the carers would provide care, when needed, on an implicit, traditional assumption that they will be cared for reciprocally when they need care (Blau, 1964; Kelley, & Thibaut, 1959; Thibaut & Kelly, 1978). In the case of HIV and AIDS, however, the death of a PLWHA is a distinct possibility (or indeed a probability), and no future reciprocity can be expected. An older caregiver may nevertheless anticipate reciprocal care and companionship from grandchildren for whom he/she cares, when he/she is very old and possibly frail, and in need of care. Hence, caregiving may be viewed within a social exchange theory framework as an undertaking involving both material or tangible and non-tangible emotional transactions in social exchanges, but a notion of equitable reciprocity may be variable (Bumagin & Hirn, 2001). In such cases, social exchange theory may no longer be applicable

2.2.2 Feminist theory

Feminist theory offers a view of events, practices, attitudes and behaviour as a collective process of discrimination against women. It is a political discourse aimed at equal rights and legal protection for women. The collective feminist theories are concerned with issues of gender differences, and advocate equality for women, protection of their rights and interests, and prevention of their exploitation. The theories argue, for instance, that women's work such as caregiving is allocated a lower social status and is regarded as unpaid labour (Canfield, 1997; Humm, 1990; Michael, 2007).

Indeed, feminist theorists argue that gender should be a primary consideration in understanding ageing and older persons because women make up the majority of older adults, and because older women are disproportionately affected by poverty and chronic illness. In addition, community-based, long-term care of older adults depends largely on female caregivers' labour: the women are unpaid or underpaid (e.g. nurse aides, community health

workers, personal aides), and are often “invisible” (Browne, 1994, 1995, 1998; Calasanti, 1999). The demands of care provision can have negative consequences for women in old age. Key concepts of the theories are gender stratification and power structures, social networks, identity, discrimination, stereotyping and sexual objectification of women (Chodorow, 1989; Lerman, 1990; Ferreira, 1999).

Feminist theories thus promote female attributes and abilities in general. A feminist theoretical perspective is relevant to the dissertation in several regards: 1) It can provide for an understanding of the nature of gender inequalities in HIV and AIDS affected households; 2) it may be used to examine older women's social and lived experiences in the era of HIV and AIDS, and 3) it can help to understand disparities, or deep gender divides in patriarchal African society.

However, the exposition of feminist theory above has been criticised for being Western oriented, which narrows the topic of feminism to purely a struggle between men and women for equality in all spheres of life (Canfield, 1997; Chodorow, 1989/91). Feminists in the developing world view women’s situation not only as the result of unequal gender relations, but as a consequence of a wide range of oppressive situations that transcend gender categories, and are related to race, class and citizenship (Uma, 1997; Meyers, 2000; Mohaty, 2003; Davis, 2004). In sub-Saharan Africa, for example, a greater number of women, especially older women, than men head their household, and care for sick children: without resources such as land, education, opportunities for employment and health care. As a result, they may experience particular stresses and have particular support needs.

Feminist theories lend themselves eminently moreover to employment in conjunction with social exchange theory. Thus, a theoretical analytical and explanatory framework drawing on both theoretical traditions for this dissertation will contribute to achieving a deeper understanding of the older caregivers’ situations.

2.3. THE SITUATION OF OLDER CARERS IN SUB-SAHARAN AFRICA AND SOUTH AFRICA

The situation of older persons affected by the HIV and AIDS epidemics in sub-Saharan Africa (SSA) has been investigated fairly extensively, but mainly through small-scale studies in specific settings. Effects of the epidemics have been found to impact affected older persons lives in multiple ways. International agencies monitoring the spread of the disease show that the SSA sub-region is worst affected by the pandemic globally (UNAIDS, 2004a; 2006; WHO, 2002a; HAI, 2003a). Understanding the situation, concerns and challenges of affected older persons in the sub-region, specifically in South Africa, and in relation to caregiving in particular, calls for expanded knowledge in relevant areas (Knodel et al., 2002; HAI, 2003a; Nusberg, 2006).

Several sub-Saharan African countries are among the world's poorest countries. The countries have limited state resources, and are hampered in their ability to provide infrastructure required to support significant intervention in the lives of citizens infected with and affected by AIDS (Callaghy, 1993; Therkildsen & Semboja, 1995; Clapham, 1996). The absence of a well developed public health service in many of the affected countries means that the burden of caring for PLWHA and supporting OVC falls primarily on the family, and increasingly on older female members, as numerous younger family members, traditionally care providers, succumb to the disease (Barnett & Blaikie, 1992; HAI, 2003a; Knodel et al., 2002; WHO, 2002; Maher, 2006). However, as argued by feminist theorists, caregiving to PLWHA and OVC is overwhelmingly a female occupation, is assigned a lower status and is acknowledged as a sub-stratum of women's unpaid labour (Canfield, 1997). Consequently, caregiving is viewed as "unimportant" activity and not contributing to the country's overall economic development – which may be partial reasons why older caregivers are not supported by the state.

In most sub-Saharan African countries hospitals tend to be concentrated in urban centres, far from rural areas where the majority of older persons live, and who have difficulty in paying for transport to reach a health centre and obtain health services (Joubert & Bradshaw, 2001; HAI, 2003b; Mwape, 2003; International AIDS Alliance, 2003; WHO, 2002; Akintola, 2004). Although health policy in some SSA countries, including South Africa, exempts the

payment of fees for health care for children younger than six years and social pensioners at primary level, the policy is often not implemented at the facilities (HAIKenya, 2001; HAI Kenya, 2003; HAI, 2004a; HAI, 2002-2005).

Older clients' health needs are often marginalised in health care services (United Nations, 2007a), which renders them vulnerable as a group. The burden of HIV and AIDS related caregiving worsens their already difficult socio-economic situation and general wellbeing. Numerous older carers suffer financial, emotional, physical and sexual abuse by PLWHA. Many older carers are unemployed, through age discrimination employment policies or because of caregiving responsibilities. Certainly, caregiving by older persons comes at a great cost to them on a number of levels, since they become virtually isolated from opportunities that could help them replenish losses they incur through caregiving. Social exchange theorists view such a situation as an unreciprocated transaction since the carer receives no benefits for the efforts he/she puts into caregiving. Worst of it all is that some female carers are accused of witchcraft and suffer dire consequences of the allegations, such as having to flee their home and area, and even be at risk of being killed (Forrester-Kibunga, 1999; Forrester-Kibunga & Dianga, 2000**;** James, 2004; Fouad, 2004; Noumbissi, 2004; Niehaus, 2001; Hoffman, 2004; Ferreira, 2004; WHO, 2002).

2.4 CROSS-CUTTING ISSUES IN CAREGIVING RELATING TO HIV AND AIDS

Several studies have identified issues relating to caregiving rendered by older persons to PLWHA and OVC due to HIV and AIDS in the sub-region (Ankrah, 1993; Ferreira et al., 2001; HAI, 2002a, 2004; International HIV/AIDS Alliance, 2003; Mwape, 2003; WHO, 2002a). The majority of the studies have described the burden of care, and the multiple and complex responsibilities that older caregivers carry and tasks they perform, as well as the contributions they make overall. Among the issues are chronic poverty, specific challenges in rural and urban settings, gender related factors, human rights issues, unsatisfactory living arrangements; social security problems; stigma and discrimination (HAI, 2003b; HAI-Kenya, 2002; Heslop & Gorman, 2002; Makiwane et al., 2004; Schatz & Ogunmefun, 2005; WHO, 2002a). The issues are elaborated below.

2.4.1 Poverty and caregiving

In sub-Saharan Africa, older people are among the poorest of the poor, and effects of HIV and AIDS worsen their economic situation further (Barnett & Whiteside, 2002; Booysen, 2002; HAI, 2003a; Steinberg et al., 2002). Given the protracted period of morbidity before a PLWHA succumbs to the disease – or in Barnett's classification, a "long-wave disaster" (Barnett & Blaikie, 1992), older caregivers are often left physically exhausted, and indebted through expenses relating to AIDS treatments and subsequent costly funerals (Barnett & Blaikie, 1992; Deininger et al., 2001; Schatz & Ogunmefun, 2005). The responsibility for meeting such debts invariably falls on an older caregiver. Older person headed households affected by AIDS in SSA countries typically find themselves in a downward economic spiral (HAI, 2003a, 2005; Akintola, 2004).

Chronic poverty compromises older carers' ability to care adequately for themselves, PLWHA and orphaned children left behind. They experience difficulty in obtaining sufficient food, clothes and shelter, and paying for health care, and have limited access to education services and transport (Ferreira et al., 2001; HAI, 2003a; Heslop & Gorman, 2002; Maher, 2006). A survey of AIDS affected households in northern Uganda found that for 65 per cent of households in which an adult aged 20-39 years had died, the most grave consequence of the death was the household's "financial ruin." (Ayiga et al., 1999). This characterisation of such households was slightly higher than for cases where the death was due to a cause other than AIDS (Ayiga et al., 1999 in Knodel et al., 2002; Ngalula et al., 2001). Indeed, the loss of remittances from a deceased breadwinner as a result of AIDS in a household, who in most cases worked and earned income in an urban area, may be expected to affect the standard of living of both the older carer and the household (Knodel et al., 2002; WHO, 2002a; Akintola, 2004; Kimuna, 2004). As devastating as the disease is, the HIV and AIDS epidemics in SSA have opened a window of opportunity to challenge and address the gendered nature of caregiving and inequalities between males and females in the region. The non-remuneration of caregiving, from a feminist perspective, is an indication of a patriarchal society which fails to value women's contribution within the home environment. To attest to the costly nature of caregiving for the actors, a study conducted by the Kaiser Foundation in South Africa found that 66 per cent of affected households had lost their main source of income due to HIV and AIDS related morbidity or mortality, and almost half reported having insufficient food (Steinberg et al., 2002). A study of older caregivers in Khayelitsha, a highly affected suburb

in the Western Cape, found that all households cited financial difficulties as the most serious problem they had to deal with (Ferreira et al., 2001). While half the respondents received a social pension, the other half were younger than 60 years and not eligible for pension benefits. The carers related their difficulties to "poverty" and "no income." Poverty is even more stark among older caregivers in rural areas (Barnett & Whiteside, 2002; Williams, 2003). Being old, they have limited opportunity for income generation; live in poor housing with inadequate security; are often isolated and have difficulty in accessing support resources; are unable to work their fields, and sow and harvest crops – because able-bodied kin have migrated or died; and face the consequences of droughts, pestilence, theft of livestock and poor health (Barnett & Blaikie, 1992; Barnett & Whiteside, 2002; HAI, 2003b).

2.4.2 Caregiving in urban areas and rural areas

Hence, challenges of caregiving faced by older carers who reside in urban areas and rural areas may differ. Older carers in rural areas are affected by the rural to urban migration of young, able bodied men and women, who seek job and education opportunities in an urban centre, which apart from a loss of support, results in large numbers of older family members becoming primary carers to young and sometimes disabled children left in their care (HAI, 2001; Tewodros, 2004; HAI, 2005a). In Mozambique, which has a long history of labour migration to South Africa, a study by HelpAge International found that "…migration of young adults results in older persons often looking after grandchildren or other sometimes sick dependants for long periods of time" (HAI, 2003b). Some studies have highlighted the implications of migration of younger kin for older carers. The carers are left behind in a rural area with limited resources, yet have to take care of sick and dying adult kin when they return to their rural home from an urban area (Dayton & Ainsworth, 2002; Knodel & Saengtienchai, 2001).

Rural areas are generally under resourced relative to urban areas, and are typically characterised by poor infrastructure, roads, dams, electricity supply and telecommunication (Kimuna, 2004). The geographical distance between most urban areas and rural areas in sub-Saharan Africa moreover limits accessibility to support from well resourced urban areas and makes it difficult for urban based kin to send remittances to elderly parents, depriving them of income and complicating caregiving further (HAI, 2004b; HAI, n.d.; WHO, 2002b). Older

persons in urban areas are better informed about HIV and AIDS than their counterparts in rural areas **(**HAI, 2004c; BOLD, 2006).

Thus, wide disparities exist in the social and economic conditions of older persons and their households in rural areas and urban areas of sub-Saharan Africa. These disparities are often due to greater investment in towns and cities, which stimulates economic growth and employment opportunities. As a consequence, rural-based young men and women are attracted to urban areas, thereby denying rural areas support and development from young and dynamic inhabitants (Barnet & Blaikie, 1992; Nhongo, 2004; Rees, 1989; Tewodros, 2004). Although an increasing number of older persons in rural areas provide care with limited resources and under difficult conditions, there is no evidence of a corresponding rise in formal support for these caregivers.

Support for older persons in non-urban and urban settings varies. In non-urban areas, older persons depend largely on a traditional kinship support system or network, and help is provided when needed by extended family and members of the surrounding community (Okoye, 2004). In urban areas, older persons may depend on non-profit organisations and municipalities for services, as well as members of their immediate family for assistance with daily needs and activities (Kimuna, 2004). Given disparities between the resource bases of urban areas and non-urban areas, this study will attempt to highlight crucial resource needs and coping mechanisms in the areas, respectively.

Certainly, the disparities are exacerbated by the migration of kin from non-urban to urban areas. In terms of social exchange theory, an older person may be disadvantaged by his/her locality in a non-urban area if no support is forthcoming from urban kin (Emerson, 1976**)**. Hence, a caregiver's support network within a non-urban area and his/her contributions are not reciprocated.

2.4.3 Gender and caregiving

In much of sub-Saharan Africa, women continue to live under strong patriachal influence and are effectively treated as second class citizens (AIDS Law Project, n.d; Schoepf, 1988; Kaleeba, et al., 1991; Standing & Kisekka, 1989; Kimuna, 2004). Many older women lack the right to inherit land and property that could serve as a resource to sustain themselves and those under their care (AIDS Law Project, n.d; Hardy, 1999; Coopoo, 2000; HAI,

2003b/2005a; William & Tamale, 1991). The task of caring for PLWHA generally falls primarily upon women, in congruence with women's traditional roles of caring for the sick and for household members (De Bruyn, 1992; HAI, 2003b; Hoffman, 2004; Okoye, 2004). The assumed gender roles between the sexes certainly serve to perpetuate an imbalance in a power relationship between men and women, such as men being the head of the household and therefore making decisions on the roles that each family member must perform, with women inevitably assigned caregiving as one of their roles.

Some researchers have suggested that AIDS creates a "grandmothers' disease," because of the disproportionate burden of care the epidemic places on them (Beer et al., 1988; Adamchak et al., 1991; WHO, 2002a; Nusberg, 2006). Older women must adjust their daily lives to accommodate new caregiving responsibilities (PANOS, 1990; Ferreira et al., 2001; HAI, 2005; Makiwane et al., 2004). The greater part of caregiving to PLWHA and orphans is indeed provided by older people, and up to 90 per cent of that care is provided by women (UNAIDS/UNPFA/UNIFEM, 2004). Two-thirds of caregivers in surveyed households in southern Africa have been found to be female, almost a quarter aged 60 years and over (UN Secretary-General's Task Force on Women and AIDS, 2004). Hence, female older carers in SSA play a crucial role in the survival and sustainability of AIDS affected families and communities (Burman, 1996; HelpAge, 2003b; Akintola, 2004).

In southern Uganda, Seeley et al. (1993) found more principal and assistant caregivers were women (56 %) than men (44 %). Also in Uganda, Kaleeba et al. (1991) observed that PLWHA whose mothers are still living tend to live longest, whilst those without a female relative survived for a much shorter period. The strain of caregiving on older women is however particularly severe where they live alone and without spousal support: such women are often poorer, depend more on friendship and goodwill, and are less entitled to, or able to access work opportunities than elderly men (Barnett & Blaikie, 1992). In instances where grandparents cannot afford to send all their orphaned grandchildren to school, boys are more likely than girls to go to school; the education of females has a lower priority in a patriarchy than male education (World Bank, 1993; Sagner, 2000). Indeed, such differential treatment of boys and girls perpetuates a power imbalance between the sexes into old age, with the scales tipped in favour of the boy child.

Some research however, suggests that the notion that men assume less responsibility for caregiving may be a stereotype. A few studies have focused on caregiving by men in the context of HIV and AIDS, and have acknowledged that men play a greater role in this regard than realised (Jackson, 2002; UNAIDS, 2000a). Although caring for PLWHA is thus performed largely by older women, older men also play a role. A few studies have examined shared caregiving by spouses, although some of the studies identified gender based roles within shared caregiving (Horizons, 2004b; Maher, 2006; WHO, 2002a). Older women have been found to provide mainly palliative care to sick persons, including food preparation and feeding, washing and changing bedding, and administering medicine. Older men have been found to provide financial and other types of material support, to run errands, and to make decisions about the care of the PLWHA (HAI, 2002b; Dlamini, 2005; Horizon, 2004; WHO, 2002a). Evidence from South Africa (Steinberg et al., 2002) and Uganda (Akintola, 2004) suggests that some men employ and pay for the services of people to care for their sick relative while they go out to work. It has not been shown, however, to what extent older men are directly involved in the care of PLWHA. The empirical study as a part of this dissertation would therefore not be limited to female older caregivers, but would seek to provide evidence of care roles played and contributions made in such caregiving by older men.

Other types of caregiving rendered by older persons, such as the care of children or grandchildren with a mental disability, are also relevant to this review. Engelhardt, Brubaker and Lutzer (1998) pointed out that parents are able to provide better care for their children if they themselves receive help or support; a subjective assessment of their own ability to provide care for their sick child was significantly related to how much they utilised outside support services, as opposed to the degree of the child's disability or characteristics of the caregiver. Yet other investigators have established that as a caregiver grows older, his or her informal support system weakens and the elder is no longer available to provide services as previously (Heller & Factor, 1993; Akintola, 2004).

2.4.4 Caregiving and human rights

Informal and non-formal caregiving at a micro level and a meso level is encouraged by governments and civil society as a key element in the management of the HIV and AIDS pandemic, especially in a context of inadequate resources (HAI, 2006a). However, informal care is stressful to carers and may be deficient for recipients. Safeguarding the human rights

of both PLWHA and older caregivers is therefore an essential component in the effective management of the HIV and AIDS epidemics (HAI, 2003b; UNAIDS, 2004b).

> *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood* (Universal Declaration of Human Rights, 1948, Article 11).

Instruments of international bodies such as the United Nations (UN) provide for the protection and promotion of the rights of older persons. The UN Vienna Plan on Ageing (UN, 1982) gives guidelines in respect of Member States' obligations regarding older persons' rights. The UN Principles for Older Persons (UN, 1991) provides for the protection of their rights to independence, participation, dignity, respect and care. Article 24 of the African Charter on Human and Peoples' Rights states that "All peoples have the right to a general satisfactory environment favourable to their development." Thus, by implication all of these rights are to be enjoyed by PLWHA as well as those affected by HIV and AIDS. The rights are reiterated in the UN Madrid International Plan of Action on Ageing (UN, 2002b). The majority of older persons in sub-Saharan Africa are unaware of the provisions to protect their rights in the international instruments, and hence neither demand nor exercise these rights (UN, 2003; Troisi, 2004).

In South Africa, older persons are sometimes described as one of the most vulnerable sections of the population. Yet, apart of large cash transfers to the older population in the form of the social old age grant, they are consistently overlooked in the allocation of other social resources, such as housing (HAI, 2001). Among rights that the country's constitution guarantees all citizens the right to education and information, the right to access to health care, and the right to not be unfairly discriminated against. Section 29(1) of the constitution states that everyone has the right to be educated (Mbazira, 2006), but the right is violated where older persons are excluded in campaigns to inform and educate citizens on the risks of HIV infection and caring for a PLWHA (Tewodros, 2004; Maher, 2006; UNAIDS/WHO, 2005).

Globally, persons aged 50 years and over who care for PLWHA and affected children are at risk of infection with the virus, but are invisible insofar as they are omitted in official HIV and AIDS statistics (Jackson, 2002; WHO, 2002a; HAI, 2003b; UNAIDS, 2004). Older

caregivers lack information and resources to reduce their susceptibility to infection. Mostly, information on HIV prevention, and counseling, support and care are directed at the section of the population (aged 15-49 years) viewed as sexually active and therefore at greatest risk of infection (Knodel et al., 2001; HAI, 2004c; Maher, 2006). Hence, older persons are not viewed as sexually active nor at risk of infection with the HI virus, and are excluded, or overlooked in programmes.

The systematic exclusion of older persons in data collection, training and services relating to HIV and AIDS moreover removes opportunities for them to obtain information to promote awareness and prevention, and where to access care and treatment for PLWHA (HAI, 2003b) - which situation violates their right to equitable access to services (United Nations, 2001; Tewodros, 2004; Tewodros & Nhongo, 2006:33). Besides, literacy levels among older caregivers in the majority of SSA countries are low, which limits their access to written information that is available. Older caregivers are thus left largely uninformed about HIV and AIDS and how it is spread, which diminishes a perception of their being at risk, and leaves them vulnerable to infection, and unable to protect themselves and those in their care (Knodel et al., 2001; Barnett & Whiteside, 2002; Foster, 2002; HAI, 2003b/2004a; Msimang, 2003). Neither is information on anti-retroviral therapy (ART) targeted at older persons; assumed not to be at risk of infection, they would neither have equitable access to ART if infected. Besides, the majority of infected older persons are only diagnosed with the disease at an advanced stage, when ARV treatment will no longer be effective (Linsk, 1994; Zelenetz & Epstein, 1998; Szirony, 1999; Wooten-Bielski, 1999).

No HIV and AIDS interventions of the South African government make explicit reference to older people as a target group at risk of contracting the virus, even if they are caregivers to PLWHA. Notable is a lack of routine screening for persons aged 50 years and over at routine surveillance sites, such as voluntary counselling and testing centres (VCT), and the non-inclusion of these persons in national syphilis and HIV prevalence rates reports (DoH, 2003/04/05; HAI, 2006b).

2.4.5 Living arrangements and caregiving

Living arrangements of older persons largely determine the support they enjoy from kin and their well-being. In SSA countries, older persons typically reside in multigenerational

households. Co-residence with younger family members is viewed as part of a "lifetime reciprocity" arrangement in which children traditionally help their aged parents in exchange for parental support at various stages in the children's lives (Cowgill, 1986; Cowgill & Holmes, 1972; Albert & Cattell, 1994; Lesthaeghe, 1983; Nhongo, 2004). However, family structures in these countries are changing, away from the extended family structure and system. The urbanisation of young adult kin is one such change trends which impacts traditional kin structures. New family forms are nevertheless evolving, such as nuclear families, mainly in urban areas, but which may no longer guarantee older members the care and support their counterparts enjoyed previously – and may have anticipated receiving in old age. Indeed, in many households affected by AIDS, numerous older members are thrust back into the role of primary caregivers, no longer care recipients (Ferreira et al., 2001; WHO, 2002a; Makhubalo et al., 2004; Maher, 2006).

Skipped-generation households, in which both middle-generation parents are absent – either due to migration, or mortality relating to HIV and AIDS or other conditions, are increasingly common in SSA countries (Barnett & Blaikie, 1992; UN, 2005). Older persons, especially older women, who co-reside with and care for orphans in such households have been found to have a low well-being index (HAI, 2003a; UN, 2005). Neither is their investment in caring for the PLWHA likely to be reciprocated with care, when they are old, from a PLWHA who will eventually die (HAI, 2006a). After the PLWHA dies, older carers may find themselves destitute and without any support (SA-PPA, 1997; Goodwin, 1999; UNAIDS, 2000a; Beresford, 2002; Rehle & Shisana, 2003; UN, 2005). Indeed, given the pressure of caregiving for a household member with a prolonged illness such as AIDS, a carer's partner or spouse may desert her and the household, thus diminishing the household's ability to cope with the effects of the disease even further (Barnett & Blaikie, 1992; Ferreira et al., 2001). The caregiving role performed by older persons may be viewed, or understood not in terms of material tangible reciprocity, but non-tangible benefits (Homans, 1961), since the PLWHA will inevitably succumb to the disease. The only benefit an older caregiver will gain is satisfaction of having helped a loved one in need. Similarly, filial relationship would be a motivation for the carer to care for OVC, which could be understood as a future investment, to benefit the older carer when he/she needs care due to frailty or ill-health.

2.4.6 Social security and caregiving

The presence of individuals with HIV and AIDS in a household strains already limited resources and the capacity of older members to care for other sick household members, orphans and vulnerable children. The loss of a PLWHA who was a breadwinner severely reduces a household's income (HAI, 2003a). Of SSA countries most affected by HIV and AIDS, only six – Botswana, Lesotho, Mauritius, Namibia, Senegal and South Africa – have a comprehensive social protection programme, typically in the form of a basic non-contributory old age pension (Giese et al., 2003; HAI, 2003b/2006b). In some SSA countries that provide no social security or social assistance for poor older citizens, these persons must rely on family or personal livelihoods for financial support. Several older carers turn to informal, or community based money saving schemes, but which are risky, difficult to manage and unreliable (Chima et al., 2004; Tewodros, 2004).

Of SSA countries that provide a non-contributory social pension, South Africa's programme is unique in its near universality and relative generosity (Ferreira, 1999). Along with that of Brazil, South Africa's programme is the most expansive in the developing world (Barrientos & Lloyd-Sherlock, 2003). In 2008, women aged 60 years and over and men aged 63 years and over were eligible, based on an income and assets means test, to receive a pension, or social grant of R940 a month (Mbola, 2008). Prior to 2008, the age of eligibility for men was 65 years, but parity in the age of eligibility is being phased in progressively; by 2010, all men aged 60 years and over will be eligible for an old age grant (Mbola, 2008). Interestingly, although South African society has historically been patriarchal in its outlook, gender discrimination regarding the pension worked against men and favoured women in terms of age eligibility. Although the old age pension (OAP) is targeted at older persons, studies show that the income is used widely to support entire households (Case & Deaton, 1996; Moller & Sotshongaye, 1996; Ferreira; 1999; Case, 2001; Sogaula et al., 2002; Barrientos & Lloyd-Sherlock, 2003; Moller & Ferreira, 2003; Makiwane et al., 2004). Beneficiaries employ the income to pay or utilities, school fees and transport, and medical expenses, and to buy food and school uniforms for household members. In some cases, beneficiaries share pension income with family members who live elsewhere (Case, 2001; Giese et al., 2003; HAI, 2004b; Sogaula et al., 2002).

Thus, social pension income provides a regular and reliable source of income to beneficiaries and their households (May, 2003; Giese et al., 2003; Maher, 2006). It serves moreover to

protect the health of all household members in households that pool income (Case, 2004; Maher, 2006). In South Africa, female beneficiaries have been found to distribute the income more widely than male beneficiaries (Duflo, 2003). Duflo (2003) found, for example, that young girls' anthropometric status (i.e. weight versus height and height versus age) was significantly improved where female beneficiaries shared pension income with household members, but male beneficiaries' pension income had no significant similar impact on either boys or girls.

Clearly, the OAP is a safety net and a lifeline for many older person headed households, especially in which orphans and vulnerable children reside, and in households otherwise rendered vulnerable and impoverished by HIV and AIDS. Typical expenditure items of female beneficiaries are special nutritious foods, medications and dressings, and transport to take the PLWHA to a clinic or hospital (Maher, 2006).

Notwithstanding the value and benefits of the OAP to beneficiaries and their household, the social grants programme is beset with a number of challenges, among which have been a largely unsatisfactory payment system and non-coverage of all eligible older persons (Barrientos & Lloyd-Sherlock, 2003). Pensions are mainly paid through a contracted third party, the South African Social Security Agency (SASSA), and the monitoring of the pension service delivery is carried out by government (Sapa, 2005). Anecdotal evidence from the mass media indicates that beneficiaries may be robbed at paypoints, or their pension money taken from them by money lenders, or "loan sharks" who wait at the pay points to claim reimbursement of loans (Commision for Gender Equality, 2005; Sapa, 2005). Apart from beneficiary related problems are ongoing challenges of the information technology system, bureaucracy, ineffective administration and fraud by administrators (Sapa, 2005). Literature on the extension of social security, in the form of special grants, to households affects by AIDS in SSA countries is scarce. Very few of the countries indeed provide a social pension to older persons, but is it neither well known whether any assistance is available to vulnerable households. The South African government provides a number of other grants, apart from the social pension, to categories of eligible beneficiaries, some of which income is used to support OVC. These grants include the child support grant, the foster care grant, the care dependency grant and the disability grant (Giese et al., 2003; Sapa, 2005). Some international studies have found a correlation between household income, including grants, and the well-being of children (Baydar & Brooks-Gunn, 1994; Meyer, 2002; Rawlston, 2000).

All social grants payable in South Africa are means tested, based on an applicant's income and assets. In the case of a social pension, the means test is applied to the income and assets of the couple, if the applicant is married. In the case of most other grants, the total income of a household is taken into account in determining an applicant's eligibility for a grant. The child support grant is designed to target vulnerable children up to 15 years, in 2008, who are living in poverty (Mbola, 2008). The number of children benefiting from the grant increased from 34 471 in 1999 to over 5.5 million in 2005 (Sapa, 2005) – and 8.3 million were estimated to benefit in 2008 (DoSD, 2008). The foster care grant is intended to address the needs of orphans or other vulnerable children, and is intended to target children up to the age of 18 years who have been placed in the care of a foster parent by a court of law. Only foster parents of children placed in their care through a court of law, and not family members of the child, are eligible for this grant (Guthrie, 2000; Children's Institute, 2002; Giese et al., 2003).

The state disability grant, which covers disabled persons – including those disabled by AIDS, has been in existence since the 2001/2002 financial year. Its purpose is to provide financial assistance to persons with a severe disability. However, with respect to AIDS afflicted person, the grant is withdrawn when their condition improves or their CD4 count is above 200 units. In addition, beneficiaries of the grant, and/or their family are supplied with food parcels and supplements, cooked meals, bereavement support and assistance with funerals (Sapa, 2005). However, caregivers to PLWHA who are eligible for the grant experience a number of barriers in accessing the disability grant (Giese et al., 2003; Nattras, 2005; Booysen & van der Berg, 2005).

Barriers to accessing a grant include an inability to provide official documents such as a bar-coded ID and a birth certificate; half of all children in South Africa do not have a birth certificate, and numerous applications for one, in order to apply for a grant, are dogged by extended bureaucratic delays (Children's Institute, 2002; Smart, 2000). Some authors argue that the value of grants, such as the child support grant, is set at too low a level to have a meaningful effect on poverty alleviation in beneficiaries' households (Bredenkamp, 1999; HAI, 1999a; Sagner, 2000). Children who are HIV positive are legally excluded from eligibility for a care dependency grant unless they have become so ill as to require permanent home care (Giese et al., 2003). The narrow legislated purpose of the care dependency grant, unclear eligibility criteria and cumbersome assessment procedures also add to the grant's inaccessibility (Child Health Policy Institute & The Children's Rights Project, 2000).

An additional challenge for the grant system as well as to beneficiaries is fraud. Citizens who are not *bona fide* beneficiaries apply for and receive a grant. Officials within the Department of Social Development and crime syndicates similarly may defraud the system (Vapi, 2004; Sapa, 2005; Skweyiya, 2007). Hence, a number of bureaucratic barriers and systemic challenges reduce the uptake of grants by people who need such assistance, especially members of households affected by AIDS (Cassiem & Streak, 2001; Children's Institute, 2002; Van der Berg & Bredenkamp, 2002).

2.4.7 Social services provided to older persons

In addition to the old age grant, the state subsidises certain services, provides certain assistance in kind, and subsidises housing in the form of old age homes or frail care facilities for state pension beneficiaries. It does not provide formal housing specifically for older persons who are able to live independently as such; indeed, shelter is increasingly unaffordable to the majority of non-institutionalised poor older persons who depend on the social pension (CGE, 2005). In the majority of African communities the concept of institutional care for older family members is rejected culturally; caring for elders at home is viewed as a kin responsibility (Ekpeyong, 1995; Ohuche & Littrell, 1989). Old age homes neither accommodate grandparents with young grandchildren, which living arrangement many older persons in South Africa prefer (CGE, 2005). Policy has determined that residential care facilities may only accommodate frail older persons in need of 24-hour nursing care, and a small number of socially indigent persons who have no alternative shelter. In South Africa, old age homes were previously racially segregated and very few homes served the black population. Historically, black older persons, who constitute the majority of the older population, have not resided in such homes; the homes have historically been occupied primarily by whites and coloureds. More recently, a demand for residential care facilities in the black population has been noted. However, the facilities, which by law are now racially integrated, are typically distant from areas where black people have lived historically, and older persons who need shelter are reluctant to relocate to these places (Ferreira, 2008 personal communication). In sum, black older persons, who as a group are worst affected by the effects of AIDS, have limited access to residential care when they need it.

The state of housing infrastructure, especially shacks and mud homes, in which the majority of older persons in South Africa reside is moreover poor. The houses are typically small and cramped; leak during rainy winter months and swelter in hot summer months; are in need of repair; and lack piped water and flush sanitation - especially in rural areas. Such housing is not conducive to satisfactory caregiving, and in fact exacerbates difficulties associated with caregiving.

2.4.8 Stigma and discrimination of affected households

Older people experience social exclusion generally. However, when PLWHA and OVC co-reside in a household, all members experience social exclusion as a result of stigmatisation of the disease. Social ties and traditional support mechanisms may be weakened when ignorance and stigma marginalise a family affected by HIV and AIDS, leaving them ostracised, isolated and alone, and without the benefit of community support. Goffman (1963) defined stigma as an undesirable, discrediting attribute of an individual that reduces the individual's status in the eyes of society. AIDS is such an attribute – of a household, family or individual – and may result in discrimination experienced by PLWHA and the family, which engenders silence over their HIV status (Dawson et al., 1987; Johnston, 2001). Hence, prejudicial thoughts and behaviours of others, including co-workers, friends, health care providers, government officials, the community and families, regarding AIDS result in the stigmatisation of PLWHA (Cameron, 1993; Jayaraman, 1998; Zierler et al., 2000), and in most cases extend to the family of PLWHA (Jackson, 2002; Procaare, 2001; Nyblade, 2003; Akintola, 2004).

Research shows that HIV and AIDS related stigma manifests itself in multiple ways, including self-isolation, voluntary withdrawal from social interaction and shame (Alonzo & Reynolds, 1995). Some perceptions underlying stigma are that HIV and AIDS is a threat to community values, safety and solidarity (Gilmore & Somerville, 1994). Stigma may therefore extend beyond the PLWHA to the caregiver and other family members. HIV-related stigma has been particularly difficult to combat, because infected and affected persons sometimes stigmatise themselves through fear, before others stigmatise them. As a consequence, stigma may indeed facilitate the spread of the disease by denying a possibility of infection, discouraging HIV testing and undermining care efforts (Johnston, 2001; Gupta, 2003).

Stigma has been cited as one of the greatest obstacles in combating the HIV and AIDS epidemics (Aggleton, 2000; UNAIDS, 2000d). HIV infection is contagious and deadly, and is often associated with promiscuity and immorality, or perceived as God's punishment to wrongdoers (International HIV/AIDS Alliance, 2003). Moreover, social ties and traditional support mechanisms can be weakened when ignorance and stigma result in the marginalisation of a family affected by HIV and AIDS, leaving the members feeling ashamed and isolated (Anderson & Kaleeba, 1994; Akintola, 2004; Horizons, 2004b; Knodel et al., 2006). As a consequence, many older caregivers are hampered in their efforts to care for PLWHA: they are reluctant to seek help and access resources externally, and feel they are failing in their role as caregivers because they are unable to protect their families from the effects of stigmatisation (HAI, 2003a; International HIV/AIDS Alliance, 2003).

In South Africa and other affected SSA countries, negative and discriminatory attitudes of service providers such as nurses and social workers discourage caregivers from accessing support services (WHO, 2002a; Giese et al., 2003; HAI, 2003b). Media reports in South Africa and research in Uganda indicate that children infected by HIV and those whose parents died of an AIDS related illness are discriminated against, and may not be admitted into some schools because of stigma, as was the case with the late Nkosi Johnson[1] (Sapa, 2002; HAI, 2003b; Simbayi et al., 2006). Interventions to address the epidemic neither include information to help older persons address the epidemic's consequences such as stigma, discrimination and stress in their caring roles (HAI, 2003b).

Highlighting the complex nature of stigma, Jackson (2002) cautions that support provided by governments to households affected by HIV and AIDS, such as those of older caregivers, need to guard against reinforcing stigmatisation and discrimination by targeting "AIDS" household for assistance. Such targeting may result in acute levels of exclusion for older caregivers and OVC living with or related to PLWHA (HAI, 2003b).

Denial of the existence of HIV and AIDS in a family may contribute moreover to the spread of the epidemic (Badade, 1999). Caregivers typically feel a need to hide the condition of the PLWHA out of shame, and to avoid stigmatisation, discrimination and sometimes violence,

[1] The late Nkosi Johnson acquired HIV infection vertically through mother-to-child transmission and became the public face of HIV/AIDS in South Africa until his death in 2002 at the age of 12. He was a keynote speaker in the International AIDS Conference held in Durban South Africa in 2000, when he called for the provision of free anti-retroviral treatment in the public health sector.

especially against female carers. Muyinde et al. (1997) found in a Ugandan village that family members of the PLWHA insulate themselves from stigma by denying the presence of the condition in their family. Family members also ensured that the face or body of a deceased AIDS sufferer was not shown to people before burial in order to avoid embarrassing comment in the community. Hence, denial is a barrier to efforts to address the epidemic. The denial of a PLWHA's sero-status by his/her family or caregiver simply encourages the PLWHA to hide the condition and to continue to engage in high-risk behaviour (Qwane, 2001; Strydom, 2000). During the International AIDS Conference held in Durban in 2000, former President Nelson Mandela (2000) urged South Africans to break the silence, avoid denial, banish stigma and discrimination, and ensure inclusivity in the struggle against AIDS. Both stigmatisation and denial of the disease must therefore be eradicated, as they discourage individuals from assessing their personal risk of infecting others (Johnston, 2001; Siegel & Gibson, 1988). The gendered nature of the discrimination and violation of carers, in some cases, is evident in that it is women who suffer AIDS stigma related violence more than men and are hounded from their home and community most (Besley, 2005).

PART B: INFORMAL CAREGVING

2.5 INFORMAL CAREGIVING

Informal caregiving is defined here as care provided by individuals, especially family members, to chronically ill or disabled persons, and other affected and vulnerable persons, within the family, household and community, but not through an agency. Such persons, or care recipients are helped to carry out activities of daily living, such as eating and bathing, and leaving their home to visit a place of worship, to travel to consult a doctor or to take medication such as ART (Takamura & Williams, n.d.).

2.5.1 Care within the family

Traditionally, within African family settings older persons were accorded a place of honour in the lineage of the hierarchy (Nzimande, 1996). The position of honour ensured that they were not forgotten or neglected, or left uncared for by other family members. Traditionally, moreover, older members relied on younger members for financial and care support (Ekpeyong, 1995; Knodel et al., 2000; Stloukal, 2001). For generations, the practice in Africa of caring for the old by their children was the norm and culturally expected (Okoye, 2004). In

turn, older persons had various social obligations that involved, among other, religious guidance, socialisation of the younger generation in self conduct and behaviour, presiding over ceremonies, and the preservation and transmission of cultural and historical information – towards ensuring the well-being of their family and community (Fuglesang, 1982; Akukwe, 1992; Diof, 2000). Traditionally, older persons did not receive "charity" from their family, but existed rather in mutual beneficial supportive relationships with family members, or the clan, which strengthened family and intergenerational cohesion. Therefore, the traditional African family way of life lends itself to examination by employing tenets of social exchange theory. While young relatives may support older relatives financially, the latter will reciprocate by giving guidance and advice, socialising the young, and transferring historical information and other non-tangible but socially valuable information.

However, in the era of HIV and AIDS, roles are often reversed: affected older persons increasingly take responsibility for providing financial support to affected and vulnerable and unemployed family members, caring for the sick, and caring and providing for vulnerable and orphaned grandchildren (Ferreira et al., 2001; WHO, 2002a; Akintola, 2004). Thus, family care patterns are being reversed (Ankrah, 1993; Deininger et al., 2001; Baylies, 2002; Knodel et al., 2002; WHO, 2002c; Maher, 2006). At the same time, older women's capacity to care, especially as they grow older and are burdened with new care responsibilities, diminishes (Knodel et al., 2001; WHO, 2002a; Maher, 2006).

Notwithstanding the enormous burden of care that older carers carry, these informal caregivers are not supported by governments in sub-Saharan African countries, including South Africa (Ferreira et al., 2001; WHO, 2002a; HAI, 2003a; Knodel, 2005). Yet, informal caregiving makes onerous physical, material, psychological and emotional demands on an older carer (Ferreira et al., 2001; WHO, 2002a; Orner, 2006).

2.5.1.1 *Caregiving to orphans and vulnerable children (OVC)*

UNAIDS defines an orphan as a child under 15 years of age who has lost his/her mother (a "maternal orphan") or both parents (a "double orphan") – in this case, to AIDS (UNICEF/UNAIDS, 1999). In sub-Saharan Africa, in 2006, approximately 9 per cent of children under the age of 15 years had lost their parents to AIDS (UNAIDS, 2006). In South

Africa, in the same year, a million children under the age of 18 years were estimated to have been orphaned by the disease (Dorrington et al., 2006).

The large number of so-called AIDS orphans in the sub-region is one of the most serious problems relating to the epidemics (Goodwin, 1999). In South Africa, a survey in four provinces found that 22 per cent of children in households with a PLWHA were maternal orphans (Beresford, 2002). Orphans have been found to suffer a range of challenges, including recurrent psychological trauma – starting with the illness and death of their parents, followed by cycles of poverty, malnutrition, stigma, exploitation and often sexual abuse (Matshalaga & Powell, 2002; Aber & Richter, 2005; Simbayi et al., 2006). The magnitude of the "orphan problem," and the accelerated increase in the number of AIDS orphans in most sub-Saharan African countries earlier resulted in a rush by well-meaning non-government organisations to place orphans in orphanages. However, the response was unsustainable, given the magnitude of the problem and its cost implications, and the small number of orphanages available (Matshalaga & Powell, 2002). It is argued moreover that it is neither in the social, cultural and developmental interests of orphaned children to be institutionalised, and preferable for them to grow up in a family unit (Mwagi, 1994; Ankrah, 1993; UN, 2004b). The fact that most of the so-called "AIDS orphans" are "maternal" orphans points to the gendered nature of the scourge of the disease in South Africa. Again the disproportionate number of deaths of women from the disease suggests that women are at a higher risk of infection than men.

In light of the so-called orphan problem, international agencies and policy makers have come to realise that extended family, with the support of the surrounding community, could provide the most suitable environment for orphans in which to grow up, which is moreover probably the only viable and sustainable solution to the problem (Ankrah, 1993; UN, 2004). In 2001, as part of the UN General Assembly Special Session (UNGASS) on HIV and AIDS, UN Member States committed themselves to meeting the needs of children affected by the pandemic. The declaration emanating from this meeting recognised the importance of care, community support and treatment for an effective AIDS response. Articles 65, 66 and 67 refer specifically to children affected by AIDS (UNGASS, 2001a).

Previously, few international declarations and commitments referred to the role played by older persons in the care management of the epidemics and their value as a care resource.

Only in the early 2000s did international instruments such as Madrid International Plan of Action on Ageing (UN, 2002b) and the African Union Policy Framework and Plan of Action on Ageing (AU, 2003) call explicitly for support for older carers; since then, greater recognition has been given to their contribution as carers, but in truth, little action or support have followed.

Fairly extensive literature refers nonetheless to the involvement of older persons in the care of OVC in family settings in sub-Saharan Africa (e.g. Ferreira et al., 2001; WHO, 2002a; HAI, 2003a; Akinsola, 2004; Orner, 2006). It has been widely documented how large numbers of young OVC are cared for at home by a grandparent in his or her fifties or older, and how older persons commonly assume responsibility for the care and support of affected grandchildren (WHO, 2002a; HAI, 2003a). However, the literature refers equally to the real or potential challenges of caregiving to OVC (HAI, 2003a; UN Policy Workshop, 2004).

It is predicted that by 2010 the number of children orphaned by AIDS in SSA will rise to more than 18 million (UNAIDS, 2004a). South Africa ranks second to Nigeria with the largest number of children orphaned by AIDS. An even more interesting ranking of SSA countries is created when the proportion of AIDS orphans is calculated as a proportion of all orphans in each country. The calculations show that South Africa, as well as the majority of its neighbouring countries – Zimbabwe, Botswana and Swaziland, and Uganda in East Africa, are facing a huge problem as children orphaned by AIDS comprise nearly half or more of all orphans nationally (UNAIDS, 2004a; Simbayi et al., 2006).

Research in Mozambique, Uganda and Zimbabwe on health care, support and empowerment of older women who render care to persons infected with or affected by AIDS, such as OVC, found that when the women were provided with knowledge and skills, they became an important and effective resource in the management of the spread of HIV: for example, by educating the children in their care about HIV and AIDS (WHO, 2002a; HAI, 2003a; Akintola, 2004). However, some research has established that when orphaned children are cared for by older relatives, who are unsupported, the children become more vulnerable, and do not attend school, or else schooling is delayed (HAI, 2004b; UNAIDS, 2004b; Simbayi et al., 2006). Caregiving to orphans also creates financial, social, psychosocial and health related difficulties for the carers. How problematic the difficulties are for a carer will depend on factors such as the carer's age, gender, (previous) occupation, income level, residential

location, family circumstances and household type (HAI, 2004a). Older carers with low or no formal education have limited access to written information such as advice on how to protect themselves and OVCs from HIV infection.

2.5.2 Older persons and social capital

Social capital is human resources or capacity available to an individual through family and social ties, upon which to draw as needed. Putnam (2000) provides an inclusive notion of social capital entailing networks and ties, trust and reciprocity and community participation. A community rich in social capital would then be described as a socially cohesive, co-operative and caring community, made up of caring individuals and groups of people who work together for mutual benefit (Onyx & Leonard, 2002; Boneham & Sixsmith, 2006).

Older people provide a vast pool of social capital to their family: as knowledge bearers and educators, and through their roles as caregiver, homemaker and income earner (Gerdes, 1988; HelpAge, 2002b). In most SSA countries, and in South Africa, older persons are advisors to their family and thus able to influence them in HIV and AIDS awareness and prevention (Tewodros, & Nhongo, 2006). Older caregivers moreover provide a sense of continuity and financial support for their grandchildren when their parents have died (Gerdes, 1988; Schatz & Ogunfen, 2005).

At a community level, research has established that most older people are social capital "agents" as advisors to the community, which enables them to influence health related attitudes and behaviour such as breastfeeding practices of young mothers, and HIV and AIDS awareness and prevention campaigns (Onyx & Leonard, 2002; Akintola, 2004; Horizons, 2004b; Tewodros & Nhongo, 2006). In Uganda, Jamil and Muriisa (2004) considered the role of social capital and community responses to AIDS, and argued that Community Home Based Care (CHBC) concerned with fostering social relations between PLWHA, their caregivers and broader communities (as against individualised approaches to HIV and AIDS, such as counseling and testing), has played a crucial role in building social capital in that country. It is crucial therefore that the lived experience of older caregivers supported by CHBC is investigated in terms of how it is influenced by social capital (Knodel, 2005).

Knodel and Saengtienchai (2001) found that older parents in Thailand who had lost an adult child to AIDS reported receiving financial assistance from kin, former employers of the

PLWHA and community members to help them to meet funeral related expenses, in addition to assistance with the physical aspect of caregiving. They relied therefore on a social capital network for help and support. The caregivers were consequently able to cope better with the financial burden of AIDS related mortality in their household. In South African communities where the HIV infection rate is high, some people form support groups to co-counsel each other and affected members of their families. A "buddy" system exists in some places moreover whereby individuals infected with the virus are taken in as a friend by someone who is not infected, and encouraged to take their medications on a regular basis; such behaviour is socially approved and encouraged.

Hence, social capital may be viewed as a resource base for social exchanges. Reciprocal exchanges and benefits that occur between actors (older persons, PLWHA, OVC, neighbours, etc.) in communities and households are key elements of these social exchanges. They include social contact, networking, shared costs and social rewards. In effect, the actors (both young and old) act to ensure that the integrity and cohesion of their household remain intact, and household (and community) resources benefit all. Social capital (the network) thus operates at a higher level than the dyadic person-to-person level of social exchange (Emmerson, 1972).

On the other hand strengthening of social networks should not be viewed as a solution for all problems that caregivers face. These networks, which represent social capital, may not be reliable or dependable, and reciprocity could be problematic (Kutz, 2004). In certain contexts, social capital as a source of support may be a "mixed blessing": it may come at a high cost to the individual. Advocates who promote of social networks as a solution to easing the strain of caregiving on older persons should thus be circumspect, and vulnerable caregivers should not be unintentionally exposed to even more stress.

2.5.3 Care and support needs of older persons

Notwithstanding the valuable role that older persons play as caregivers, their personal resources are limited, and the literature has defined a range of areas of concern and need for them. Among these areas is support to enable the carers to sustain their caregiving (Maher, 2006). Recent research has established care and support needs of older caregivers of PLWHA and OVC in some sub-Saharan countries, including South Africa, from the older carers'

perspective (Ferreira et al., 2001; WHO, 2002a; Makiwane et al., 2004; HAI, 2005c; Maher, 2006).

In Zimbabwe, a World Health Organization survey (WHO, 2002a) on AIDS and older people found that nearly two-thirds of caregivers identified finance as their greatest need. Research in Kaloma district in Zambia and Tanzania supported this finding, and established that cash transfers to caregivers prevented their household from sliding into deeper poverty (Department for International Development, UK, 2005; HAI, 2001; Ntozi & Nakayama, 1999). Multi-country studies and consultations conducted by HelpAge International found that although older persons are aware of AIDS, the majority lack accurate information on its causation (HAI Kenya, 2003, 2005c, 2006a). Some studies found that older carers need support with legal matters, such as issues of conflict, property rights and eligibility to social security benefits (Ferreira et al., 2001; Jackson, 2002; Tewodros & Nhongo, 2006; WHO, 2002a). In South Africa, no policy provisions are available for older persons who care for PLWHA and/or OVC, which support is essential if the burden of care on affected older persons is to be addressed.

PART C: NON FORMAL CAREGIVING

2.6 NON-FORMAL CAREGIVING

Non-formal care is defined here as caregiving provided by non-profit organisations (NPOs), such as faith based organisations (FBOs) and community home based care (CHBC) organisations. Non-formal care is delivered through interaction between community support mechanisms and NPOs, often with links to welfare and public health services, and is aimed at meeting the health, physical, psychological, emotional, social and spiritual needs of persons who are sick or disabled (WHO, 2006; UNAIDS, 2004b). This type of care is provided at a meso, or community level, rather than at a household or family level. Non-profit organisations take a variety of forms, depending on the jurisdiction and legal system of a country, and an NPO's goals (HAI, 2003b).

2.6.1 Non-profit organisation (NPO) care initiatives in the community

At a meso level, HIV and AIDS affect the "social body" (Barnett & Blaikie, 1992; Frohlich, 2005): that is, the relationships between affected families and the broader community are

impacted negatively by effects of the disease. An example of such impact would be where stigma and discrimination of PLWHA are directed against the family (Jackson, 2002; Procaare, 2001; Nyblade, 2003; Akintola, 2004). Consequently, a main mechanism for managing the epidemics in affected SSA countries has taken the form of co-operation between local communities and non-profit organisations (NPOs), through education, information sharing, counselling, income generation, material support and awareness campaigns (Barnett & Blaikie, 1992; Jackson & Kerkhoven, 1995; Woelk et al., 1997; Wilson, 2000; Jackson, 2002; Steinberg et al., 2002; Horizons, 2003).

In sub-Saharan African countries, community based home care (CBHC) is largely provided by NPOs, sometimes supported by government – which is typically the case in South Africa. Community based home care has emerged as an effective method for delivering non-formal, compassionate care to those infected and affected by HIV and AIDS, such as older caregivers (UNAIDS, 1997; Jackson, 2002; Akintola, 2004; Peltzer et al., 2006). In South Africa, the slow implementation of certain elements of the national response to HIV and AIDS, such as the roll-out of ART, and structural limitations of the public health and welfare systems, have contributed to growing support and care for PLWHA and their families in the community by NPOs (Birdsall & Kelly, 2005; Peltzer et al., 2006). Two NPOs that work closely with older caregivers affected by HIV and AIDS in South Africa are Grandmothers Against Poverty and AIDS (GAPA) and the Muthande Society for the Aged (MUSA). The participation of the non-profit sector in the fight against the disease at the meso level complements the fight at the micro, or household level. Non-profit organisations share their resources (manpower, information on HIV/AIDS, networking, provision of physical space, etc.) freely, in exchange for the co-operation and loyalty of the community they serve, to fulfil a common purpose (Lohman, 1992), such as containing the spread of HIV within a particular community. According to social exchange theory, the NPOs' actions are therefore motivated by a desire to encourage voluntary action for the benefit of all concerned within a community. Most importantly, they aim to enhance affected individuals' quality of life and extend survival for the PLWHA

2.6.2 Interface between NPOs, government and donor agencies

Non-profit organisations rely largely on government and international donor agencies, such as the Global AIDS Fund, ActionAid, the European Union (EU), Oxfam and HelpAge International, for information, material support and funding to sustain their activities,

including remuneration of staff (Jackson, 2002; Peltzer et al., n.d.). Non-profit organisations that deliver services on behalf of the government to affected communities experience a number of challenges, however. In South Africa, the organisations experience bottlenecks or delays in the distribution of funds, which impact service delivery negatively (Save the Children, 2006; Phaswana-Mafuya et al., 2008). Research evidence indicates that donor agencies must deal with complex procedures and application forms, and stringent requirements that are often incompatible with an NPO's activities. Most NPOs do not have the capacity to administer large amounts of funding (Jackson, 2002; Save the Children, 2005).

However, research also shows that NPOs are most valuable and effective if they work with, rather than parallel to, governments (UNAIDS, 2004b; Phaswana-Mafuya et al., 2008). It is argued that both sides need to be open to partnerships, and it is up to the governments to create a positive environment in which NPOs may function freely within their communities (UNAIDS, 2004b). Some authors point out that state agencies have found it difficult to work with non-profit organisations because of limited capacity, such as financial management skills, inability to meet rigid agency accountability guidelines, and costing, such as audited financial reports (Lenton et al., 2003; Mpanju- Shumbusho, 2003; Peltzer, et al., n.d.). Research indicates moreover that, in addition to the problems in partnering with government, NPOs tend to focus on competing with each other for funds and credibility within communities they serve, rather than forging a cohesive voice within the non-profit fraternity (International AIDS Alliance, 2002; Jackson, 2002). Other challenges faced by NPOs are problems of low coverage and referral of patients to other levels of care, either due to non-recognition by welfare or health care providers (Jackson, 2002; Akintola, 2004). Drew et al. (1997) estimated that most home care programmes attain only about a 1-2 per cent coverage. Wilson (2000) cites a study by Banda of seven home care projects in Zambia that found that the 1 268 clients enrolled for care represented only 4.5 per cent of the estimated 28, 000 clients in the catchment area. Woelk et al. (1997) reviewed 33 home care programmes in Zimbabwe and also found low coverage: estimated at 2-4 per cent. Moreover, NPOs generally depend on volunteers from communities to serve as labour and receive limited support from government (Akintola, 2004; Friedman, 2002). The volunteers in turn rely strongly on extended family members of a PLWHA, especially grandparents, to provide ongoing treatment to the PLWHA and to care for grandchildren (Giese et al., 2003; Akintola, 2004; WHO, 2002b). Some authors argue that NPOs need to work and see themselves as part

of a continuum of care for the PLWHA, and should link up with health clinics in the serviced community (Jackson, 2002).

Other difficulties that NPOs face relate to the quality of care provided and referral systems (Jackson, 2002). In the Woelk et al. (1997) review, the authors found that only 17 out of 33 programmes, almost half, provided even a basic minimum package of care. An ideal care package was defined as including a greater focus on caregiver training, HIV prevention, wider integration with long-term services for OVC and better direct patient care and referral (Jackson, 2002).

Nonetheless, some authors point out that services provided by NPOs are accessible to clients and their caregivers, reduce isolation and provide needed interventions, which can contribute to improved health care seeking behaviour, better quality of life and extended survival for the PLWHA (Russell & Schneider, 2000; Stephenson & Hennink, 2004). This observation is evidenced in the involvement of PLWHA and their caregivers in AIDS care, treatment, literacy and education activities, and their ability to anticipate the health and material needs of the community (Gilks et al., 1998; Blinkhoff et al., 1999; Oleja, 1999; Birdsall & Kelly, 2005; HAI; 2005). In addition, non-formal methods of education and awareness raising applied by NPOs, such as songs, storytelling, and community theatre and/or drama, offer mechanisms for health education that is culturally acceptable, effective, affordable and accessible (WHO, 1978; Shaik & Hatcher, 2004). These non-formal methods of active learning are compatible with, and promote the general principles of Primary Health Care (WHO, 1978).

Non-profit organisations that provide community home base care are especially active in prevention and care programmes that reach isolated communities and households in many sub-Saharan African countries affected by HIV and AIDS, including South Africa (Blinkhoff, 1999; Russell & Schneider, 2000; Nsutebu, 2001; Jackson, 2002; UNAIDS, 2004). The services provided are diverse, although not mutually exclusive. Services range from home visits and nursing, information distribution and counseling, to income generation and skills development (Jackson, 2002). Research has shown that when care and support are provided, especially at a community level, people are less likely to deny their HIV status, will understand a need for prevention, increase their health seeking behaviour, and will be motivated to protect others; than when no services such as those offered by NPOs are

provided, and they feel neglected by both the formal and non-formal health care system (MacNeil & Anderson, 1998; HAI, 2005c).

Thus, the literature highlights major care gaps in NPO service delivery, which include among other a lack of discharge plans from hospital to home, a lack of family and caregiver preparation, insufficient numbers of visits to the PLWHA's homes, a lack of material provision to the caregiver to provide optimal care- including foodstuff and, medication, a lack of legal advice to caregivers on issues such as disability grants and application forms, and referral to social, legal and medical services (Jackson, 2000; Ray & Mataure, 2000; WHO, 2002a, Giese et al., 2003; Akintola, 2004).

2.6.3 Non-profit organisation best practices

The notion of best practice involves the identification and use of a successful intervention or knowledge about that which has proven to work well in certain situations and contexts. In other words, best practices involve both the lessons learned, and a continuing process of learning, feedback, reflection and analysis of the situation (UNAIDS, 1999). An intervention may be viewed as a best practice if it is sustainable, and can be replicated in certain other settings, with adjustment if needed.

The literature describes a range of NPO best practices involved in supporting PLWHA and their families. In sub-Saharan Africa, best practices that are functioning well and are being replicated in different settings, such as rural and urban environments, are found in some of the sub-region's most under-served areas such as peri-urban and farming communities (Russell & Schneider, 2000; Friedman, 2002; Akinola, 2004). Examples of NPO best practices that have proven to be effective in countries in the sub-region are:

- *Grandmothers Against Poverty and AIDS (GAPA)* in South Africa. GAPA was established, based on the outcome of a longitudinal qualitative study undertaken by the Institute of Ageing in Africa (IAA) to assess the needs of grandmothers affected by HIV and AIDS, in 2000/2001. It was later registered as an NPO. GAPA organises peer support groups for affected grandmothers, and capacitates them through education and information on HIV and AIDS, and human rights, and equips them with life skills and income generation skills. Within support groups, grandmothers share information, ideas and skills that help them to cope better with their situation.

They make handicrafts and other items which they sell in their community and benefit from the income. The GAPA model is replicated in other provinces in the country.

- *Magunje* in Zimbabwe. Magunje is an income generation project for people infected with and affected by HIV and AIDS. Established by HelpAge International (Jazdowska, 1992), it capacitates caregivers through skills training in garment making, poultry faming, etc. Its members sew school uniforms, rear and sell chickens, and build irrigation systems. An aim is to encourage older people and school children to work together to promote intergenerational solidarity.
- The *Catholic Diocese Outreach Project* in Ndola, Zambia copperbelt. The project offers training to volunteers in home-based care and support to infected and affected persons, and their caregivers. Trainees are later dispatched in their communities to train and assist affected families, and empower older carers through knowledge and information on HIV and AIDS, who in turn educate their peers on the disease (Blinkhoff et al., 1999).

A key lesson to be drawn from NPO best practices that support older carers is that support for and work with older persons can benefit others. Non-profit organisations thus clearly contribute to the support of older carers in their struggle against the epidemics. They not only equip the carers with critical skills and knowledge needed to manage PLWHA, but also assist them to break away from the drudgery and routine demands of caregiving (Miller, 2000). Indeed, the literature shows that NPOs are at the forefront in mitigating the impact of the epidemics on older persons and their households (Akintola, 2004; Ferreira et al., 2001; HAI, 2003a, 2004b; 2006b). In addition, they lessen the burden of care on overstretched public health systems. However, they need material, human, infrastructural and financial resources, to enable them to improve or overcome some of their limitations such as poor coverage (Drew et al., 1997).

2.6.4 NPOs as advocates for HIV and AIDS caregivers

Advocacy aims to influence decision making with a goal to develop, establish or change policies, and to establish and sustain programmes and services (WHO, 2004). Non-profit organisations are involved in community mobilisation and the protection of PLWHA' human rights, and facilitate access to health, welfare services and education (UNAIDS, 1997; Russell & Schneider, 2000). Some NPOs such as GAPA and the Treatment Action Campaign

(TAC) in South Africa lobby government ministries and submit petitions highlighting the plight and support needs of infected and affected persons, including older caregivers.

In Mozambique, some CHBC work with older carers and schools to demand subsidization of school fees for OVC. Other CHBCs lobby district education authorities and schools to help re-integrate OVC into schools (HAI, 2002a, 2003a), thus assisting older carers and improving OVC's situation and life chances. In South Africa, advocacy organisations in KwaZulu-Natal such as MUSA and Thandanani identify caregivers and households affected by HIV and AIDS and children at risk of being orphaned and vulnerable, and then create awareness, and establish links and referral relationships with relevant bodies such as social, medical, nutritional, child welfare and other support services in the community (Russell & Schneider, 2000; Sanders et al., 2005; Maher, 2006).

Research indicates that emotional and psychological support, albeit to a limited extent, is commonly provided by CHBC NPOs. Support groups empower older people by building self esteem, network, raise the visibility of older women caregivers and encourage mutual support (UNAIDS, 1999; Nokes et al., 2006). Issues of belonging, participation, access to formal sources, and identification with the local community as well as empowerment to promote change within the community may be important yet unexplored aspects of empowering and supporting older caregivers in the management of the epidemics (Boneham & Sixsmith, 2006; Knodel et al., 2006).

PART D: FORMAL CARE

2.7 FORMAL CARE

Formal care is defined here as caregiving provided by professionals to clients through an agency, either in the public sector or the private sector, for which services professionals are compensated. Categories of formal care providers range from medical practitioners to registered nurses, therapists, social workers, dieticians and paraprofessionals such as nurse aides (Allander & Spradley, 2005). The majority of formal care professionals work in public health institutions at the primary level of the health service system.

2.7.1 Primary Health Care (PHC) approach

Primary Health Care emphasises the centrality of comprehensive, inter-sectoral action among sectors such as health, education, welfare, agriculture, housing, business and community involvement in identifying and solving community (and household) health problems (WHO, 1978; Last, 1988; McCoy & Engelbrecht, 1999; WHO, 2003).

Some literature has indicated that the multiple and complex problems presented by HIV and AIDS in communities in sub-Saharan Africa call for a PHC approach (Akinsola, 2001; WHO, 2006). Such approaches include helping individuals to recognise the severity of the HIV and AIDS epidemics in the community (Akinsola, 2001). The WHO supports a primary health model of service delivery for HIV and AIDS services that will maximise the role of PHC, and promote a developmental agenda with an emphasis on community empowerment and participation (Rifkin & Walt, 1986; WHO, 2006). However, comprehensive PHC has not been achieved in many developing countries, although based on principles of effectiveness, equity, social justice, community involvement, mainly due to a lack of interest on the part of funders in investing in acute health interventions that are likely to achieve only short-term and immediate health improvements (Zwarenstein & Baron, 1992; Baum & Sanders, 1995; WHO, 1996).

Research carried out in Botswana indicates that when PHC personnel support family members affected by HIV and AIDS with appropriate information, such as how to access available resources in their communities and establish effective social networks, hope in the future is restored for both the PLWHA and the family (Akinsola, 2001; Horizons, 2004c; UN, 2004b). Work done in other affected developing countries such as south India, indicates that comprehensive support by government and NPOs to PLWHA and their caregivers alleviates the burden on caregivers. In south India, districts provide medical services, counselling, nutrition, dental care, social support and referral services to relevant government institutions and traditional medicine services (Horizons, 2004c).

In South Africa the PHC system began in earnest in 1994, with an explicit goal of developing a unified national Health System that is organised at national, provincial and district levels. The PHC system provides free health services to pregnant mothers, children under five years of age and older persons. Health clinics have been built in urban centres and rural areas to

increase access to primary-level health care (Pillay et al., 1998; Department of Health, 2000; Joubert & Bradshaw, 2000; Benatar, 2004). The primary care services provided free to eligible clients at over 3 500 PHC clinics include prevention, and the care and treatment of diseases of older persons (DoH, 2000; Joubert & Bradshaw, 2000). However, in the transformation of South Africa's health services to PHC, dedicated older person services were largely marginalised or even withdrawn. The few remaining services are concentrated in urban areas and thus inaccessible to older persons in rural areas (Joubert & Bradshaw, 2000; Benatar, 2004), where the majority of older caregivers reside.

Research indicates that such marginalisation includes the preventive, curative and rehabilitative needs of older clients, which for the main part have been integrated into general sessions at community clinics at primary care level (Benatar, 2004). Moreover, numerous community nurses were redeployed from geriatric services to assist in child immunisation programmes (Benatar, 2004). Client dissatisfaction with services at public health institutes is documented in a number of studies (Myburg et al., 2005; Westaway, 2003; Wouter et al., 2001; Househam, 2009). The grievances include long waiting times, client overload, poor staff attitudes and morale, referral problems and shortages of medicines.

Certainly, the PHC system and its associated challenges do not currently meet the health needs of older caregivers to PLWHA and OVC. They are neither enabled to sustain or improve their own health. Older caregivers suffer a number of physical and mental health problems, relating to caregiving, over and above ailments common in old age, and diminishing energy and stamina. Among these conditions are swollen limbs, hypertension, headaches, dizziness, chest pains and stomach disorders (Valenti, 1995; WHO, 2002a; Dayton & Ainsworth, 2002). Emotional problems include anxiety, insomnia, stress, burn out, and feeling over-burdened (WHO, 2002a; Maher, 2006; Knodel, 2006).

Intervention efforts such as training and integrating older caregivers in PHC service delivery have been undertaken in some developing countries – in Mozambique, Botswana and India, for example (HAI, 2003a; Akintola, 2004; Horizons, 2004c). An evaluation of such interventions indicates that older persons become an important and effective resource in the prevention and mitigation of the spread of HIV and AIDS (HAI, 2003a; WHO, 2002a). Thus, an opportunity exists in South Africa for PHC, with its principle of community involvement, to do more for older caregivers. Indeed, avenues along which caregivers' capacity and

willingness to help their sick children may be utilized need to be explored. They may then be trained and involved in counseling programmes and monitoring treatment adherence at home as has been demonstrated in other highly affected countries such as Botswana and Mozambique. Policy on PHC, and inclusion (or exclusion) of older clients in policies are reviewed fully in Chapter 3.

2.8 OLDER CAREGIVERS' KNOWLEDGE ON HIV AND AIDS

As noted above, the literature provides evidence of the major challenge that HIV and AIDS poses for older caregivers, families and communities, as well as Primary Health Care in the SSA region and South Africa. Among SSA countries, South Africa carries the second heaviest burden of HIV and AIDS after Swaziland (UNAIDS, 2004a/06). Despite extensive international research, no cure for the disease has been found. Progress in the area of HIV infection prevention was shown in scientific papers presented at the Toronto XVI 2006 HIV and AIDS international conference. Of interest is that scientific papers on caregiving presented in the conference indicated that older carers, especially older women in Africa, experience great hardship and lack resources to help them in their caregiving, and thus support them and the contribution they make.

The prevalence of HIV continues to escalate in some world regions, especially in poverty stricken developing regions of sub-Saharan Africa (UNAIDS, 2006). At a micro level, individuals and families have difficulty in coping with the stresses of related caregiving. At a meso level, the resources of NPOs are over stretched as they try to meet needs and demands of communities affected by the epidemics. At a macro level, formal care systems, specifically the PHC system in South Africa, experiences similar difficulty in trying to manage the epidemics, as shown in Human Sciences Research Council (HSRC), national surveys (Shisana & Simbayi, 2002, Shisana et al., 2005) and Department of Health ante-natal syphlis surveys (2004,2005). Seemingly, non-profit organisations, through their CHBC programmes, have come to the rescue of the overstretched PHC system, but have their own limitations, such as a dependency on volunteers, low coverage, a limited technical skills base and financial constraints.

Affected older persons who ultimately carry the burden of care for PLWHA and their grandchildren at a household level thus form a crucial part of the informal safety net on

which PLWHA and OVC ultimately rely. Older women render a valuable contribution to the care management of HIV and AIDS (PANOS, 1990; Ferreira et al., 2001; HAI, 2005c) and within the family and affected households, and in this way are a crucial link in the continuum of care to PLWHA and OVC. Thus, it is widely argued in the literature that older carers should be supported, to enable them to cope with the double burden of caregiving and old age (Joubert & Bradshaw, 2000; HAI, 2003a; Knodel & Im-em, 2004; Orner, 2006).

As several authors have indicated, decisions on the nature of such support should be informed by an understanding of the complex situation of older caregivers. The support should be targeted moreover to resources within and outside relevant households. Goals such as strengthening the family, removing barriers to social assistance, inclusive and effective health services, improved economic environments, and social networks for parenting grandparents are factors that have been highlighted (Dolbin-MacNab & Targ, 2003; Hayslip & Kaminski, 2005).

Policies on AIDS and older persons' integration in such policies and responses are reviewed in Chapter 3. The review of the relevant literature in Chapter 2 has pointed to a need to respond to the situation and support needs of older carers, against the provisions of international, continental, sub-regional and national bodies, and an identification of gaps in policy action.

CHAPTER THREE: REVIEW OF RELEVANT INTERNATIONAL, REGIONAL AND NATIONAL INSTRUMENTS, POLICIES AND PROGRAMMES

3.1 INTRODUCTION

A review is undertaken in this chapter of international and Africa regional instruments, policy frameworks, and national policies and programmes aimed at the advancement of older individuals' human rights, development and support in general, and responses to persons affected by HIV and AIDS in particular. The review includes national sectoral policies, strategic plans and programmes, and legislation, as part of African governments' response in their commitment to employing and implementing the international and regional instruments. In addition, community responses to the support needs of older persons in the era of HIV and AIDS are examined.

The review is aimed overall at an identification of strengths and weaknesses of existing, frameworks, policies and programmes: in particular, gaps in responses to the support needs of older persons rendered vulnerable by the epidemic. The review will serve as a basis for the development later in this dissertation of an appropriate policy framework to guide policy reformulation or development to support such persons. Policies on HIV and AIDS, ageing and older persons, human development and Primary Health Care are reviewed. Gaps in these policies, particularly the exclusion of affected older persons, are identified as are opportunities to fill the gaps, specifically through Primary Health Care strategies and interventions, identified.

3.2 INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

Instruments to protect the human rights of individuals have been developed by international bodies such as the United Nations (UN). Such instruments include the UN Declaration of Human Rights (1948), the UN Principles for Older Persons (1991), and the Vienna Declaration (1993) - adopted in the World Conference on Human Rights. Human development instruments, such as the UN Millennium Declaration (2000), similarly provide a basis for the protection of the rights of all, including persons afflicted with or affected by contagious diseases such as HIV, tuberculosis (TB) and other conditions. The Universal

Declaration of Human Rights (1948) embodies 30 articles that deal specifically with human rights. Article 25 emphasises the right of every individual to enjoy an adequate standard of living to ensure his/her health and well-being, or that of his/her family, and mentions older persons specifically as constituting a vulnerable group whose rights should be protected by governments. The declaration does not provide a mechanism to enforce the provisions, and Member States are left to honour their commitment to the declaration, and to be guided by the provisions in the development of policy and the implementation of programmes. In practice, however, older persons' participation in social and political processes, and their ability to exercise their human rights, vary across countries.

The Vienna Declaration on human rights (UN, 1993) emphasises the promotion and protection of individuals' human rights as a global priority. Its Programme of Action provides Member States with a framework to carry out a comprehensive analysis of their human rights system and the machinery for the protection of citizens' human rights - in order to enhance and thus promote a fuller observance of those rights in a just and balanced manner. Sections (i)(21)(22)(23) and (24) of the declaration mention the need to protect the rights of certain vulnerable groups in society such as children, disabled persons and migrants, but make no explicit reference to older persons. However, implicit in subsection (i)(24), on the promotion and protection of the rights of vulnerable groups – especially in the areas of education, health and social support, is consideration of the rights of older persons.

3.2.1 International human development instruments

Instruments that deal specifically with human development focus on poverty reduction and economic growth broadly, and are inclusive of HIV and AIDS and health care strategies intended to benefit infected and affected persons. Among these instruments are the UN Millennium Declaration (UN, 2000) and the subsequent Millennium Development Goals (MDGs) (UN, 2002); and the UN Declaration of Commitment on HIV and AIDS (2001).

The UN Millennium Declaration states that "Only through broad and sustained efforts to create a shared future, based upon our common humanity in all its diversity, can globalization be made fully inclusive and equitable" (UN, 2000). Following on the UN Millennium Declaration, was the adoption of a set of eight development goals, known as the UN Millennium Development Goals (MDGs), which constitute an action plan for the

implementation of the Declaration (UN, 2000). The MDGs have built-in targets to be achieved by signatory Member States by 2015. Broadly, the MDGs promote poverty reduction and the realisation of human rights as overarching goals for development co-operation. Although they not refer to older persons specifically, some of the goals, once achieved, may serve to improve the situation of older carers to PLWHA and OVC in sub-Saharan countries. Other goals potentially relevant to older persons are those aimed at halving the proportion of people living in poverty (MDG1) – among which are numerous older persons; redressing gender inequality and forging women's empowerment (MDG3) (see also UNFPA, 2002a; HAI, 2003a, 2004); and halting and starting to reverse the spread of HIV and AIDS (by 2015) (MDG6) (UN, 2000).

However, the MDGs focus on development of the youth. Indicators to redress gender inequality and achieve other goals are set narrowly, and in effect have an upper age limit. By focusing on education and literacy for girls and young women, for example, the goal overlooks the fact that women of all ages in sub-Saharan countries and other developing regions fall behind men in literacy and education (HAI, 2005b). A baseline study on HIV and AIDS in Bangladesh showed that older men had on average four more years of education than older women, and average incomes more than five times higher than those of women in their age group (Chaklader, 2004). Likewise, a study of gender in education in Africa (Kitetu, n.d.) established that although some African governments such as Kenya and Ghana have affirmed female education as a priority by increasing female school enrolment, females are still disadvantaged in practice by cultural gender norms (UNAIDS, 2004b). Thus, older persons are neither mentioned in the MDGs, nor are they included in development agendas (Aboderin & Ferreira, 2008).

Nonetheless, the UN Declaration of Commitment on HIV and AIDS, adopted in 2000 (UN, 2000), is aimed at addressing the problem of HIV and AIDS in all respects, and securing a global commitment to enhance co-ordination and intensification of international, regional, and national efforts to combat HIV and AIDS in a comprehensive manner. The declaration has gone some way in correcting the anomalous exclusion of older persons in the MDGs. It refers specifically, for example, to the family more than once, and in particular to older persons, in the context of the "social and economic impact of the epidemics at all levels of society". Article 68 refers specifically to women and the elderly in their role as caregivers in families affected by HIV and AIDS. It also addresses their special needs, such as a need for

social protection, essential economic services and other relevant support measures specifically relating to caregiving. The declaration calls for various role players, globally, regionally and nationally, as well as governments, business, non-profit organisations, communities and donor agencies to work together to combat HIV and AIDS, and to ensure the universal principles of participation, non-discrimination, and the human rights of those infected with and affected by HIV and AIDS. Thus, the declaration provides explicitly for older persons' integration into these processes.

3.2.2 Internationally agreed policies and plans relating to older persons' needs

Instruments that focus specifically on older persons include the UN Principles for Older Persons, adopted in 1991 (UN, 1991). The document embodies five main principles for the realisation of older persons' rights: i) Independence, which includes access to adequate food, water, shelter, clothing and health care; ii) Participation, which intends that older persons should participate actively in the formulation and implementation of policies that affect their wellbeing and should share their knowledge and skills with younger generations, as well as be able to form organisations and associations; iii) Care, which proclaims that older persons should benefit from family care, health care and be able to enjoy human rights and fundamental freedoms when resident in a shelter, care or treatment facility; iv) Self-fulfilment, which states that older persons should pursue opportunities to develop their potential fully, through access to educational, cultural, spiritual and recreational resources within their society; and v) Dignity, which states that older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse, and should be treated fairly and be valued independently of their economic contribution (UN, 1999). The UN International Year of Older Persons, celebrated in 1999, supported the Principles for Older Persons as proclamations in recognition of humanity's demographic “coming of age” (UN, 1999).

More recently, the UN Madrid International Plan of Action on Ageing 2002 (MIPAA) was adopted by 159 Member States within the Second World Assembly on Ageing, held in Madrid, Spain in 2002. The MIPAA has three priority directions (see UN, 2002b): a) Older persons and development; b) Advancing health and well-being into old age; and c) Creating an enabling and supportive environment. According to the first priority area, the expectations of older persons and the economic needs of society demand that older persons be enabled to

participate in the economic, political, social and cultural life of their community. Hence, poverty reduction strategies must increase their focus on the poorest and most vulnerable older persons, especially older women, and enable them to achieve their basic human rights and to live in dignity (UNFPA, 2002a). In this respect, the empowerment of older persons and the promotion of their full participation in society are essential elements in the fight against older persons' poverty, especially where they are affected by HIV and AIDS.

The second priority area, which promotes the advancement of health and well-being into old age, declares that older persons should be enabled to access preventive and curative care, including rehabilitative care and sexual health care. The priority emphasises the importance of health care services for the older population, including the training of personnel and facilities to meet the special needs of the older population. The third priority direction calls for the creation of enabling and supportive environments for older persons in order to enhance their capabilities, which includes access to basic services such as clean water and adequate food (UN, 2002b). An overall thrust of MIPAA is that older persons should be fully included in development efforts and programmes aimed at reducing poverty and forging development – as both contributors to and beneficiaries of such efforts.

The MIPAA has a section on HIV and AIDS that commits Member States to recognise the contribution that older persons make to development in their role as caregivers to sick adult children and as surrogate parents to young children orphaned as a result of the disease. The instrument encourages governments to improve their assessment of the impact of the disease on older persons and to "introduce policies to provide in-kind support, health care and loans to older caregivers to assist them in meeting the needs of [adult] children and grandchildren in accordance with the Millennium Declaration Goals" (UN, 2000). Furthermore, it calls for adequate information, training in caregiving skills, medical treatment and care, and social support to older caregivers. It argues specifically for the enhancement and recognition of older persons' contribution to development and their roles as caregivers in the era of HIV and AIDS.

A strength of the MIPAA in this regard lies in its focus on contributions made by older persons affected by HIV and AIDS and their related support needs. The plan of action makes important policy connections moreover between older caregivers' needs and the needs of the

children for whom they care. Significantly, the plan commits signatory governments to extend to older persons the "right to development."

3.2.3 International HIV and AIDS instruments in response to the epidemics and older persons' needs

The UN Declaration of Commitment on HIV and AIDS was adopted by the General Assembly in its 26th special session held in June 2001, convened in accordance with resolution 55/13, as a matter of urgency, to review and address the challenge of HIV and AIDS. The declaration notes that "the full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV and AIDS pandemics". It also sets concrete, time-bound targets for the introduction of national legislation and other measures to ensure the respect of rights in regard to education, inheritance, employment, health care, social and health services, prevention, support, treatment, information and legal protection. A strength of the instrument lies in its encouragement of national governments to develop legislation to protect the rights of infected and affected persons. Older persons are implicitly recognised in the instrument, as it mentions the realisation of human rights and universal freedoms for all. However, Member States are not legally bound to implement commitments in the declaration.

The Valletta Declaration (UN/HtA, 2005), on the other hand, developed in an expert meeting within the Commonwealth People's Forum held in Malta in 2005, aimed to draw attention to the effects of HIV and AIDS on older persons among heads of state and to influence the development of policy to mitigate these effects throughout the Commonwealth (of which South Africa is a member). A particular strength of the declaration lies in its being the first global instrument to focus specifically on older persons and HIV and AIDS, and to call for dedicated policy to support affected and infected older individuals. Other strengths lie in its ten recommendations, which call *inter alia* for the integration of older persons' support needs in general with their social and household needs. The recommendations are addressed to governments and civil society, six of which deal specifically with the support needs of older caregivers.

The first recommendation calls on governments to recognise older caregivers by providing them with political, social and economic support' without this recognition, they will

otherwise be excluded in HIV and AIDS policy and programme development and implementation. Recommendations 2 and 6 call on both governments and civil society to incorporate affected and infected older persons' needs in their responses to HIV and AIDS, as their needs are similar to those of the broad society. The recommendations call for responses that promote intergenerational cohesion. Thus, older persons' needs should not be addressed in isolation or as a vertical programme, but integrated within other interventions. Recommendation 7 emphasises the importance of appropriate prevention and education strategies targeted to, and/or potentially mediated by, older persons. Recommendation 8 calls on governments and international bodies to support research on the impact of HIV and AIDS on older persons, including the collection and disaggregation of data on infection rates by age and gender. Recommendation 9 urges formal and informal institutions, in tandem with the media, to play an active role in the eradication of stigma surrounding persons and households affected by HIV and AIDS. Lastly, Recommendation 10 calls on governments to introduce and implement policies that make anti-retroviral therapies available to all who need them, including older persons and those in their care. A particular strength of the Valletta Declaration lies in its recognition of a need to address HIV and AIDS related problems through an intergenerational solidarity approach. Thus, the exclusion of any section of society, especially older persons, in responses to the epidemics is to be discouraged.

3.2.4 Primary Health Care, HIV and AIDS, and older persons' needs

The Primary Health Care (PHC) strategy, defined as "essential health care based on practical, scientifically sound and socially acceptable, appropriate strategies and technologies, easily accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of development …", was adopted in Alma Ata in 1978 (see WHO, 2003). Consequently, Member States should commit themselves to providing and ensuring "health for all" by the year 2000. However, in sub-Saharan African countries the PHC policy provisions have been more symbolic than real (UNDP, 1991).

Nonetheless, the adoption of the PHC strategy by the World Health Organization was a milestone in the formulation of health care delivery policy globally. It was envisaged that the first level of contact for individuals, the family and community with the national health system should be at the local level. Thereafter, patients could be referred, if needed, for

investigation and treatment at secondary and/or tertiary health care levels. Primary Health Care comprises eight elements: i) Education concerning prevailing health problems and methods of preventing and controlling them; ii) promotion of food supply and proper nutrition; iii) adequate supply of safe water and basic sanitation; iv) maternal and child health care, including family planning; v) immunization against major infectious diseases; vi) prevention and control of locally endemic diseases; vii) appropriate treatment of common diseases and injuries; and viii) provision of essential drugs (WHO, 1978). Coupled with the elements are principles underlying PHC, which are in accordance with principles promoted in the international human rights instrument (1948) such as social justice, equity, human dignity, and giving priority to the most vulnerable groups in society. However, the extent to which PHC policies in SSA countries encompass equity, community participation, inter-sectoral collaboration and affordability is questionable. Nonetheless, a major strength of the PHC approach lies in its recognition and prioritisation of the health care needs of vulnerable groups, such as the poor, among which is a large number of older persons (UN, 2001b).

Significantly, the WHO has developed a document that promotes age-friendly PHC, namely 'Towards Age-friendly Primary Health Care' (WHO, 2004a). The "age-friendly" principles built upon in the document address four major areas: i) Information, education, communication and training, including staff training in clinical geriatrics and approaches to patient education; ii) health care management systems, i.e. adaptation of procedures, such as registration, to the special needs of older persons; iii) adoption by PHC of systems that support a continuum of care both at the community level and at secondary and tertiary care levels, including the keeping of records of the client and the provision of social services to the clients; and iv) the physical environment, i.e. accessible and easily readable signage, and clean and comfortable centres (WHO, 2004a).

Despite their strengths, the implementation of the PHC principles 30 years after their adoption has been variable in many developing countries, especially in sub-Saharan Africa. Inadequacies in the translation of policies into implementable programmes are contended to have contributed to, if not produced, poor national health outcomes across the sub-region (Dugbatey, 1999). This impasse is largely due to a lack of resources; internal and cross border migration trends that stretch limited public health resources; and the emergence of communicable diseases such as HIV (WHO, 2003).

The governments of several SSA countries have been slow moreover to implement provisions of international instruments, through a lack of awareness or commitment, a lack of political will, and/or a selective, as opposed to a comprehensive, approach in programme implementation owing to a lack of resources (both financial and human) (De Maeseneer et al., n.d.).

3.3 AFRICA REGIONAL INSTRUMENTS

At a regional level, Africa's responses to human rights, human development, health and the HIV and AIDS epidemics are informed by regional inter-governmental agencies such as the African Union, sub-regional bodies such as Southern African Development Countries (SADC), and strategies such as those of the New Partnership for Africa's Development (NEPAD). In conjunction with the availability of the instruments for policy and practice in general, are specific instruments for honouring the rights and responding to the needs of older persons.

Regional bodies that have developed policies and responses represent governments, coalitions of civil societies, community based organisations, youth, the media and the private sector as stakeholders. However, while various regional role players have been involved in the drafting of the instruments, older persons and organisations that represent them have tended to be overlooked and excluded (African Union, 2003; Du Guerny, 2001). Such oversight may be due to “ageist” attitudes, whereby older persons are viewed as a spent force and approaching the end of their life (Nhongo, 2003). Thus, older persons tend to be viewed largely as welfare beneficiaries and dependents, rather than as contributors to family, community, social and economic life, but who, as in the present case, may be actively involved in addressing and managing social problems such as HIV and AIDS and other developmental challenges (HAI, 2002a).

3.3.1 Regional human rights instruments and older persons' rights

The African Union (AU), previously the Organisation of African Union (OAU), is the main regional body charged with the development of Africa-wide binding instruments. Among these instruments is the African Charter on Human and Peoples' Rights (the Banjul Charter), adopted in Nairobi, Kenya in 1981 (OAU, 1981). The charter was drafted as a result of a

concern of regional heads of state about a lack of respect shown to the rights of Africa's citizens by their leaders. However, the generality of the charter's provisions is similar to that of rhetoric of the African Union, regarding, for example, women's rights (Rebouche, 2006), which many sub-Saharan African countries fail to respect fully. As a consequence, 27 years since its adoption, several African countries still lack a political will to respect and protect the human rights of citizens - as witnessed, for example, in the mass killings as a result of ethnic conflict in Rwanda in 1994 (Mamdhani, 2003) and continuing extreme violation of the human rights of Darfurians in Sudan. Human rights violations in Darfur have resulted in more than 700, 000 displaced persons, 10 per cent of whom are older persons (HAI, 2005a)

Nevertheless, a particular strength of the OAU charter lies in Article 2, which argues for recognition that all should enjoy the rights and freedoms in the charter without distinction of any kind, such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. More pertinently, Article 9 of the charter states that "Every individual shall have the right to receive information," relevant to his/her wellbeing and development. Article 18(4) further notes that "the aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs." A progressive document among the regional instruments is the document pertaining to the New Partnership for Africa's Development (NEPAD), discussed below.

3.3.2 Regional instruments on human development and older persons' development

In efforts to forge unity and good governance and to promote economic and social development in Africa under a single regional structure, the OAU earlier developed various instruments to give concrete form to such efforts. Among the instruments are The Lagos Plan of Action (LPA) and Final Act of Lagos (1980-2000), and the New Partnership for Africa's Development (NEPAD) (2001). The former two documents were adopted by the heads of state of countries belonging to the OAU in Nigeria, Lagos, in an extraordinary session devoted to economic problems on the continent. The LPA incorporates programmes and strategies to promote self-reliance, development and cooperation among African countries. However, the LPA makes no mention of the development of programme(s) to ease the socio-economic difficulties faced by older persons in the region, the majority of whom live on less than a dollar a day (HAI, 2005a). The plan makes no mention moreover of issues such as

human rights and support for the poor, in which group the majority of older persons fall (HAI, 2003b). The New Partnership for Africa's Development (NEPAD) was formulated as a mechanism to strengthen the aim of the LPA and other regional instruments (NEPAD, 2001). NEPAD was adopted as a programme of the African Union at the Lusaka Summit, Zambia in 2001. The document is designed to help Africa and her people to overcome regressive political regimes and to enable her to achieve peace, economic growth and development. It states that "The New Partnership for Africa's Development is a pledge by African leaders, based on common vision and a firm and shared conviction, that they have a pressing duty to eradicate poverty and to place their countries, both individually and collectively, on a path of sustainable growth and development, and at the same time, to participate actively in the world economy and body politic" (NEPAD, 2001:1). Importantly, NEPAD recognises the importance of democracy, human rights, and the rule of law for economic development explicitly. A significant improvement of NEPAD as an instrument to support development, compared to other Africa regional instruments, is that it has developed its own code of governance and system for "peer review". The document looks outward, moreover, as well as inward for solutions to development barriers in Africa. However, its pledges on human rights are vague, and it is silent on older persons' development needs.

3.3.3 Regional instruments and older persons' needs

A number of regional instruments address older persons' needs specifically. The African Union's Policy Framework and Plan of Action on Ageing, drafted parallel with the UN Madrid International Plan of Action on Ageing (MIPAA), was adopted in the 38th Ordinary Session of the Heads of State and Government in Durban, South Africa, in July 2003 (AU, 2003). The main objective of the plan is to guide AU Member States as they design, implement, monitor and evaluate appropriate integrated national policies and programmes to meet the individual and collective support needs of older persons (HAI, n.d.). The policy framework identifies barriers to older persons' well-being in the region, and provides recommendations to remove those barriers. Among issues highlighted in the policy framework are human rights. Significantly, the framework recommends that Member States abolish all forms of age-based discrimination. Regarding health, the framework, it urges Member States to undertake to ensure that older people's rights to appropriate health care are legally constituted and guaranteed. It also identifies gender as an important issue and encourages Members States to incorporate ageing into policies relating to gender. Moreover,

the framework identifies HIV and AIDS specifically as being a major problem facing older persons in Africa, and urges Member States to undertake to support affected older persons in their contribution to the fight against the disease. Finally, the framework encourages the integration of older persons' interests in state policies and interventions in general.

3.3.4 Regional HIV and AIDS instruments and older persons

HIV and AIDS related morbidity and mortality in the continent currently undermine the development efforts of African regional bodies severely. Encouragingly, the African Consensus and Plan of Action to Overcome HIV and AIDS (AFD, 2000) acknowledges the efforts of numerous role players in the fight against the epidemic. The plan emanated from a meeting between African leaders convened by the African Union and held in Addis Ababa, Ethiopia in 2000, which deliberated on ways and means to overcome the HIV and AIDS epidemic and its effects in Africa. Among the strategies proposed is the development of strong leadership at all levels of society, starting from the family and community, to national and regional levels. Clause 2.11 of the plan mentions older persons specifically as being stakeholders in the community, whose important role and responsibility must be supported and developed to enable them to become full allies in the fight against the epidemics. A particular strength of the plan lies in its call for older persons' full integration in efforts to fight the epidemics.

The Abuja Declaration (2001) emanated from a special summit of African heads of states and government of the African Union (AU), held in Abuja, Nigeria in 2001, to discuss problems presented by HIV and AIDS, tuberculosis, malaria and other infectious diseases in Africa. The declaration identifies groups at high risk of HIV infection, among whom are youth and women (i.e. young females). The declaration commits signatory governments to develop a multi-sectoral strategy to combat the epidemics, which should include sectors such as trade unions, the media, religious organisations and youth. However, the declaration is exclusive in its approach in that it overlooks older persons and their role in the care management of the epidemic in African communities and households. While youth groups and PLWHA organisations are viewed as allies in combating the spread of the epidemic, no mention is made of older persons' organisations. Nevertheless, the AU Policy Framework and Plan of Action on Ageing (2003) identifies older persons as having a role in the fight against the

epidemic and indicates 13 important areas of concern in which they need support, such as health, food and nutrition, housing and living conditions, among others.

The AU policy framework refers specifically to an urgent need to protect, support and educate older persons regarding HIV and AIDS, and to allocate more resources such as specific budget to support growing numbers of older persons caring for the sick and OVC, and families and support systems in communities. The framework includes a section on the family, and makes recommendations for the development of policies that reposition and strengthen the family to enable it to respond to the problems that affect families. Actions on HIV and AIDS recommended in the plan include: i) Ensuring that policies and programmes recognise older people as major care providers to sick family members and vulnerable and orphaned grandchildren; ii) providing support to those caring for and affected by AIDS and other epidemics; and iii) strengthening community based care mechanisms to ensure that older people who are care givers receive support. The instrument benefited markedly from the involvement of older persons' bodies such as HelpAge International's Africa Regional Development Centre in its formulation, as the centre actively canvassed older persons' opinions and gathered information on their difficulties and needs, and incorporated same in the policy framework.

A document that focuses on older persons in the era of HIV and AIDS in southern African countries is the UN Policy Framework on HIV/AIDS and Family Well-being (UN, 2004b), developed in a workshop with participants from several southern African countries, held in Windhoek, Namibia in 2004. The workshop followed on special sessions of the UN General Assembly sessions on HIV and AIDS (UN, 2001) and Social Development, aimed at developing a strategic policy framework to assist governments to strengthen the capacity of families and family networks to cope. The Namibian workshop aimed moreover to promote the achievement of Millennium Declaration Goal # 6, which deals with the combating of HIV and AIDS, malaria and other communicable diseases (Target 7: by 2015). The workshop participants explored the impact of the epidemics on families and how they cope in the sub-region specifically.

A strength of the Namibian workshop document (UN, 2004b) lies in its multigenerational approach to addressing the effects of the epidemics, that is inclusive of older persons. The workshop report, which presents a policy framework, argues that while general HIV and

AIDS policies in the sub-region address the effects of the epidemics on individuals in different age groups separately, they tend to overlook the effects on families and communities as a whole, including the specific support and other needs of older members. The report highlights the valuable contributions that older persons make to the care management of the epidemic, and that such contributions are largely unrecognised and unsupported. It proposes a shift of focus, whereby policies and programmes respond to the needs of whole families in a comprehensive way, inclusive of older members (see Ferreira, 2006), who it views older members as crucial role players in affected households. The report proposes seven desired outcomes of future policies, namely: i) Reduced risk for and prevented spread of HIV and AIDS; ii) avoided stigma and discrimination; iii) supportive family and community networks; iv) diminished economic vulnerability; v) improved care and service provision; vi) mitigated effects of a generation of orphans; and vii) intergenerational cohesion.

An important document aimed at forging development in Africa, although not developed by African leaders, is the Commission for Africa Report (CfA) (2005), which emanated from the Commission for Africa set up in 2004 by the British Prime Minister at the time. The Commission comprised 17 influential African and non African experts in the areas of politics, business, economics and other important social areas. Among pressing issues addressed were poverty, and the HIV and AIDS epidemics in the continent. Regarding the fight against AIDS, the report recommends that "special emphasis should be placed on the participation of excluded groups… such as AIDS widows, children, older persons in the design of HIV and AIDS instruments such as health policies, strategies, programmes and messages" (CfA, 2005: 199). The report argues moreover for special cash transfers to be made to older caregivers of vulnerable children, since such measures have been proven to increase school attendance by 90 per cent and to improve child nutrition in places such as Zambia and Namibia (CfA, 2005: 203). It further commits the African Union to support African countries to develop national strategies inclusive of marginalised groups. Thus, the report agrees with the notion of supporting and addressing older persons' vulnerability, not least in their role of raising "children orphaned by AIDS."

Given the availability of the above instruments and documents, and Member States' commitment to them, the task must now be for the governments of countries affected by HIV and AIDS to review their existing policies, strategic plans and programmes against such instruments; to incorporate recommendations of recent, international and regional instruments

and frameworks in policies and plans, and particularly to develop responses that will benefit older persons and their households. These actions should include an integration of social services, targeted approaches, and financial support and policies that are inclusive rather than exclusive of older caregivers.

3.3.5 Primary Health Care (PHC) and older persons' health needs

The Africa region has no specific Primary Health Care policy document. African countries have followed different strategies to adopt and implement the World Health Organization's (WHO) Primary Health Care principles. However, because of the slow pace of implementation of PHC principles in African countries, health ministries adopted the Bamako Initiative (BI) document in Mali in 1987 as a strategy to accelerate PHC implementation (WHO/UNICEF/Government of Mali, 1999). The initiative's central thrust is to revitalise PHC at district level. It focuses on three complementary issues: i) A need for PHC self-financing mechanisms at district level, especially a revolving fund for essential drugs; ii) encouragement of social initiatives to promote community participation in policies on essential drugs and child health; and iii) ensuring a regular supply of essential drugs of good quality at lowest cost in support of PHC. In 1988, the WHO formulated "Guidelines for Formulating National Drug Policies." The guidelines were first adapted for the Africa Region in 1993 and the current version (WHO/AFRO/ED/01.5) was published in 2003. The document has particular relevance in that it promotes community involvement through health committees or boards, and attempts to create an environment conducive to community participation in general. However, implementation of PHC principles at the district level relies heavily on lay persons, such as community or village health workers and traditional birth attendants – most of whom are older women, especially in under served areas such as rural areas. The BI does not offer policy proposals on how lay persons who implement PHC principles may be integrated formally in the formal health system, in respect of recruitment, training, support and supervision. Neither does it indicate how the health care needs of vulnerable groups such as older persons may be promoted and protected.

3.4 NATIONAL RESPONSES: POLICIES, STRATEGIC PLANS, PROGRAMMES AND LEGISLATION

Relevant national policies, strategic plans and programmes in response to human rights, human development, HIV and AIDS, older persons and PHC in some sub-Saharan African

countries are reviewed in this section. A specific review is then undertaken of the situation in South Africa, from an historical perspective, to assess the government's response to older persons' needs in general and to HIV and AIDS in particular. Specific ministerial responses to the epidemics such as policies, strategic plans, programmes and legislation are reviewed. Sectoral responses examined specifically are those of the Presidency, and the ministries of Social Development, Health, Education, Housing and Transport. Employment of an historical perspective is essential to a review and understanding in this case, to be able to evaluate what has been achieved and what is lacking. First, definitions are given of the concepts of policy, strategic plan, programme and legislation, as they will be used below.

A policy is a social contract in a specific area of fiscal allocation and service provision, entered into by a government with its citizens, which citizenry elected the government into place. A policy is more than an intention, or a statement of intent; it represents what the government has undertaken to act upon and to deliver to the people (Walt, 1994).

A strategic plan is an organisation's or a government's process of defining its strategy or direction, and making decisions on the allocation of resources to pursue this strategy, including economic and human capital.

A programme is a system of projects and/or services intended to meet a public need.

Legislation is a set of acts of parliament and laws intended to protect its citizens' human and legal rights against abuse or violation by authorities, other bodies and groups, and individuals (Walt, 1994).

3.4.1 Country-specific human rights codes and older persons' rights

Most countries in sub-Saharan Africa have formulated policies, plans and programmes to respond to the challenges of human rights abuse, human development, older persons' needs, Primary Health Care delivery, and the effects of the HIV and AIDS epidemics. However, as pointed out, the implementation of the policies and plans has been variable.

Under colonial rule most African people suffered abuse of their human rights. Indeed, even under post-colonial rule, new black political elites perpetuate human rights abuse against

citizens, depicted as a “culture of impunity” by international human rights bodies (Manby, 2004). Although some countries have a constitution with a bill of rights, the human rights of their citizens are still at risk of violation. In Swaziland, respect for human rights has been shown to be under threat, as shown in media reports of civil society pressing for democratic change (African Development Bank, 2005-2009).

Nonetheless, some SSA governments have attempted to redress these situations by developing policy documents to protect citizens' human rights. The Botswana government developed a constitution that bars unfair discrimination (Botswana Human Development Report, 2000). However, the document makes no mention of older persons' rights.

Some SSA countries undermine their citizens' right to participate in policy and law making processes openly. In Lesotho, the formulation of government policy and legislation takes place behind closed doors and no consultation is provided for (Lesotho Council of NGOs, 2006). By implication, vulnerable groups such as older persons and their representative organisations are excluded in processes to formulate policies and legislation that affect them.

The exclusion of certain sections of society, such as lay older persons, from the development of important national documents, such as a country's constitution, appears to be the order of day in numerous African countries. Kenya developed a draft constitution, and although a product of wide consultation, no mention is made of the involvement of older persons or their representative organisations in the drafting process (Human Rights Watch Kenya, 2005). Discrimination against PLWHA and their carers infringes on their human rights, and contributes not only to the stigmatisation of these persons but their being subjected to various forms of abuse as well. Research in four Nigerian states found evidence of discriminatory and unethical AIDS related behaviour among health professionals. Abuses included denial of care and breaches of confidentiality (UNAIDS, 2004b). Although many SSA countries have achieved a great deal in developing constitutions and policies to protect citizens’ human rights, more needs to be done to hold governments to account when they fail to uphold provisions in national instruments and commit practices that are not rights based.

3.4.2 National human development and older persons’ development needs

Sub-Saharan African countries are plagued by endemic poverty and lag behind on most development indices (Aboderin & Ferreira, 2008). Indicators show widespread poverty and

large inequalities in access to basic services. The Human Development Index (HDI) places a middle income country, Botswana, at 131 (Cleveland, 2007) in the international human development scale. Arndt and Lewis (2000) project that the gross domestic product (GDP) in South Africa will be 17 per cent lower by 2010 than it would have been without AIDS. Non-income aspects of progress reflected in such human development indicators as life expectancy have shown significant declines due to civil wars, famine, economic depression, communicable diseases, and in particular the scourge of HIV and AIDS (Williams, 2003).

While most of the countries have programmes aimed at promoting human development, few have made any effort to mainstream older persons' development needs in the programmes – or indeed to recognise their capacity to contribute to and benefit from development initiatives. In Lesotho, a National Development Plan has been formulated in line with the United Nations Development Programme (UNDP), but a report (UNDP, 1998) shows that unemployment is estimated to be over 30 per cent; over 50 per cent of the population is poor, the majority of whom are older persons and reside in rural areas (UN, 2001b). Hence, one may conclude that for whatever reasons, implementation of the development plan has been unsatisfactory.

While national development plans and policies have been formulated in most sub-Saharan African countries, much remains to be done in incorporating older persons into the plans and policies, and removing constraints on implementation (UNFPA, 2002b). Inadequacies in the translation of development policies, strategic plans and programmes into implementable activities are contended to have contributed to poor human development in the sub-region (Dugbatey, 1999). Added to this difficulty are the negative effects of HIV and AIDS on human development in the sub-region (UNAIDS, 2004b). As part of a forward looking strategy on development and ageing in developing countries, the UNFPA consistently attempts to reorient and redirect thinking about individual and population ageing. Central to this approach is recognition given to opportunities for integrating ageing into a broad development framework, that takes account of individual development as a lifelong process, multi-generational relations, and a close link between ageing and development (UNFPA, 2002b). The UNFPA's approach to human development challenges stereotypes held in discussions on older people and development, such as that of elderly people typically viewed as a constraint on development (Blaikie, 1999). Such conclusions may be drawn too hastily. Benefits accrued in being old include a wealth of skills and experience – from the workplace,

public life and family (Stloukal, 2001). More recently, such skills are applied in caring for the ill and orphaned children.

3.4.3 HIV and AIDS responses and older persons' needs

For many countries in sub-Saharan Africa, HIV and AIDS and its consequences have emerged at a historic time of endemic poverty, under development, conflict and government under-spending on public health services. HIV and AIDS exacerbate the poverty, further undermine human development, increase the number of orphans, and contribute to stigma of and discrimination against infected and affected persons UNAIDS, 2004a). Hence, national responses to address the problems brought about by the epidemics need to pay specific attention to such issues. Previous sub-sections have looked at a variety of policy issues. This sub-section reviews national responses to HIV and AIDS and older persons' needs.

When AIDS first gained international attention in the early 1980s, the WHO took a lead in identifying it as a major health concern (Jackson, 2002). Many sub-Saharan African countries have been guided in the development of their policies and strategic plans in response to the epidemics by the WHO's Global Programme on AIDS. However, national responses in sub-Saharan Africa have varied owing to resource constraints and the extent of political will to address the epidemics, even where clear scientific evidence and advice exist (Jackson, 2002; UNAIDS, 2004a). Botswana has developed a comprehensive national policy and strategic plan on HIV and AIDS, which incorporates prevention measures, and was the first country in sub-Saharan Africa that aimed to provide anti-retroviral therapy to all its needy citizens. Sadly, the country's HIV prevalence rate of 24.1 per cent is the second highest in the world, after Swaziland (UNAIDS, 2007), which suggests poor implementation of the plan.

A slow response to formulate national HIV and AIDS related documents to combat the scourge in some sub-Saharan Africa countries has increased the burden of care. Namibia drafted several HIV and AIDS policies before one was finally adopted - in 2007 (Weidlich, 2007). Kenya, albeit with a low HIV prevalence of 7 per cent (Kenya National HIV/AIDS Strategic Plan, 2006-2010), has developed an HIV and AIDS strategic plan that targets specific social groups such as discordant couples, commercial sex workers, OVC and migrants, but excludes older persons - who are themselves at risk of infection with the virus (WHO, 2002a; UNAIDS, 2004a).

Some SSA countries, in early stages of their epidemic, introduced backward, discriminatory and restrictive legislation around HIV and AIDS, aimed at segregating PLWHA. In 1996, a Nigerian military administrator reportedly ordered the arrest and confinement of all AIDS patients in his state, in the belief that this would prevent the spread of HIV (Heywood, 1999). In Swaziland, which has the highest HIV prevalence globally, 38.8 per cent, a political leader who chaired the National Council on HIV and AIDS commented in favour of segregating people with HIV and AIDS (SANASO, 2001).

3.4.4 Responses to older persons' needs in the era of HIV and AIDS

In general, most policies on older persons cover their basic needs, to an extent, such as housing, social security and pension provision – be it private, public, contributory or non-contributory. More forward looking policies make a link with wider development issues and aim to integrate ageing into other national policies. In the SSA sub-region, a need to link provisions and policies on older people with issues such as HIV and AIDS, poverty reduction, human development has been recognised (HAI, 2002a). In 1999, HelpAge International reviewed the status of national policies on ageing in 46 countries and found that only 10 had one in place. Since then, ten years later, an additional six countries have formulated a national policy framework on older persons and others have incorporated provisions for older persons in sector-specific (e.g. health) policies (Aboderin & Ferreira, 2008). Among countries that have adopted a national policy on ageing are Mozambique, Tanzania, Mali, Egypt and Tunisia. However, a number of countries have only bills on ageing and others are taking their time in developing a policy. Cameroon, Kenya, Zimbabwe, Ghana, Uganda, Zambia and South Africa still only have policy documents in draft form (HAI, 2005b). Zimbabwe started a consultation process towards developing a policy in 1992 but stalled some years ago (HAI, 2005b).The slow pace of policy formulation, despite rapid population ageing, is worrisome (HAI, 2002a). The lack of a national, comprehensive policy to support older persons' needs in most SSA countries shows an apparent lack of urgency in this regard on the part of the governments, or a deprioritisation of older persons' needs.

While progress has been made in some SSA countries in the past decade or so in strengthening old age support through the introduction, or reform of social pension or social assistance programmes, the health care needs of older persons have received little policy attention and indeed little intervention (HAI, 2002b; Caldwell, 2001). Reasons for a relative

lack of attention paid to health care policy and provision for older persons include non-recognition of their special health care needs and a need for dedicated services; consequently, few dedicated health professionals have been trained (UNFPA, 2002a). Public policies and programmes are thus needed to address the needs of the older poor who cannot afford basic services such as health care.

3.4.5 Primary Health Care (PHC) national policy formulation and older persons' health care needs

The PHC systems of some sub-Saharan Africa countries are informative in respect of what can be achieved in addressing the health needs of older persons. Older persons already constitute a significant proportion of clientele at the lower levels of the PHC system; as the population structure ages, they will become more numerous and the prevalence of chronic disease will increase (WHO, 2004c). However, older persons typically encounter numerous barriers when they seek health care. Zimbabwe operates a decentralised PHC model, and achieved major improvements in child mortality rates and nutrition in the ten years after independence (WHO, 2002a; Sanders et al., 2005) as resources were redeployed from central and general hospitals to district hospitals and clinics. Now, PHC service centres in that country remain inaccessible to numerous older persons because of long distances and lack of money for transport. The same situation applies in most southern African countries. Numerous clinics have a shortage of drugs (HAI, 2002b; WHO, 2002a). In general there is little importance assigned to the health of older persons in these countries (WHO, 2002a).

Some of the countries have plans to show their commitment to PHC principles. Kenya's plans started in 1980-1984 and were followed up in 1989-1993 (WHO, 2003); however, the plans are reported to be of no benefit to older persons, many of whom resort to consulting traditional healers for health care because of the high cost of medical treatment (HelpAge Kenya, 2001; HAI, 2002b). Corruption and bribery, and failure to implement national laws entitling older persons to free medicines further diminish the accessibility of health services to older persons (HAI, 2003b). Health care staff members at PHC centres are reported to be uncommitted to treating older clients. When some older persons visit health care centres, they are told they have a disease called "old age" (HAI, 1999b; HAI, 2002a).

In efforts to monitor the performance of their PHC systems, some SSA countries such as Swaziland have developed strategies with sets of indicators to assess the health status of children and mothers, but not that of older persons (Swaziland Ministry of Health, 1983). Clearly, although PHC in SSA countries may appear promising on paper, it is not fully supportive of older persons' health needs. Even when services are available, health and welfare professionals have little knowledge or understanding of older persons' health problems, and ageist attitudes prevent them from rendering appropriate care (HAI, 2002a; Nhongo, 2003). Thus, it appears that implementation of PHC policy provisions is largely rhetorical when it comes to addressing older persons' health care needs. Against this background, I look specifically at the South African government's policy, strategic plans, programmes and legislation to address issues of human rights, human development, HIV and AIDS, older persons and Primary Health Care in the sections below.

3.5 SOUTH AFRICAN GOVERNMENT RESPONSES TO OLDER PERSONS' NEEDS

3.5.1 Human rights and older persons

Historically, the human rights of the majority of the South African population were undermined by injustices under successive colonial administrations, and more recently the four-decades long system of "separate development," or apartheid (from 1948 to 1993). Black older persons, in particular, endured abuse of their human rights through the entire four decades and more of apartheid, through inequitable access to political power, economic resources and general human development experienced by their white counterparts. As a result, they experience cumulative disadvantage in old age. With the advent of democracy in 1994, all South Africans' human rights were protected under the new Constitution (Act 108 of 1996). Chapter 1 of the Constitution highlights the fundamental principles upon which the democracy is premised, one of which is the protection of individuals' dignity. In conjunction with the Constitution's provisions is enabling legislation which further protects citizens' human rights (see Chapter 2 of this dissertation). Specifically, under Chapter 2 (Bill of Rights), section (9) (iii), it is stated that no one must be discriminated against based on his or her age. Hence, older persons are constitutionally ensured of a right to the same treatment as persons in other age groups.

In accordance with international charters, covenants and treaties on human rights, South Africa's constitution and bill of rights include political, civil, cultural and economic rights among other rights. The constitution is comprehensive in its address and defence of human rights of all South Africans. However, although it stipulates that no one will be discriminated on grounds of age, it does not openly advance the rights of older persons. As a result, it is found in practice that older persons are consistently passed over in the allocation of resources (*Cape Argus*, 2003). Anecdotal evidence in the media shows widespread abuse of older persons, where their rights are violated and they are inadequately protected under existing laws (Commission on Gender Equality (CGE), 2005). A study commissioned by the national health department, conducted by the Africa Strategic Research Corporation (1999), found that 53 per cent of older respondents had personal experience of abuse. As a consequence, the circumstances in which many older persons in South Africa find themselves infringe on their right to dignity (CGE, 2005). Nonetheless, specific new legislation now exists to protect older persons' rights: the *Older Persons' Act* No.13 of 2006. It remains to be seen however to what extent the legislation is applied to protect the human rights of older persons in practice. The following subsection deals with human development and older persons in South Africa.

3.5.2 Human development and older persons' development

Prior to 1994, the human development needs of the majority of the South African population were overlooked for decades. The majority of citizens were residentially restricted to poor and under developed rural areas, and had little access to opportunities for self advancement. Nevertheless, in comparison to the Human Development Index (HDI) for sub-Saharan Africa in the early 2000s (0.468), South Africa's HDI (0.684) was higher (NMG-Levy Consultants, 2002). However, in 2005 the country's HDI dropped to 0.674 (Human Development Report, 2007/08). The decline in HDI is said to be partly due to AIDS related mortality, which has reduced the life expectancy component of the HDI value. Coupled with the AIDS mortality effect was lower expenditure on public education (NMG-Levy Consultants, 2002). Encouragingly, the South African government increased its expenditure on health, from 3.1 per cent of Gross National Product in 1990 to 3.7 per cent in 2000 (Garbus, 2003).

Although older persons bear many of the effects of AIDS, their changing human development needs and contributions are routinely ignored (HAI, 1998). Their contributions in the era of

HIV and AIDS are overlooked, in spite of the wealth of experience that they bring to public and family life, and evidence of their contributions to development (HAI, 1998). In South Africa, age-based retirement is mandatory, usually at 60 years; certainly, economic activity is disallowed for social pensioners (see Chapter 2) if they are to remain eligible for a social grant. This requirement – mandatory aged-based retirement – contradicts calls on governments to share a commitment to international development targets, *inter alia*, by halving the number of people in extreme poverty by the year 2015 (MDGs, 2002), as it excludes older persons from the workforce (May, 2003). Nonetheless, South Africa is making progress in efforts to achieve the MDGs: it is certainly fighting poverty and has introduced universal primary education. A UNDP report shows that the income level of the poorest has increased as a result of the country's social security programme (Johansson, 2008).

3.5.3 Responses to older persons' needs

A range of policies, programmes and legislation has been available historically to address the socio-economic, health and well-being needs of older persons in South Africa. However, earlier legislation, policies and programmes were designed primarily to address the socio-economic and social needs of economically indigent white older persons (Sagner, 2000). The introduction of the social old age pension through the *Old Age Pension Act* of 1928 was discriminatory at the outset: it provided for pensions to be paid to white and coloured older persons and not Africans and Indians (Sagner, 2000). A rationale for the discrimination at the time was that the pension programme would encourage loyalty from the white working class towards the state and would help to integrate poor whites into the economy (Sagner 2000). Subsequent to the 1928 act, the Pension Laws Amendment Bill was passed in 1944, which extended the pension to all age-eligible South Africans, but remained discriminatory in terms of the amounts paid to beneficiaries in the different race groups (Tribe, 1976; Legido-Quigley, 2003). The amount of pension benefits received by whites was four times higher than that paid to blacks, with Indians and Coloureds falling in-between: a ratio of 4: 2:1 (Legido-Quigley, 2003).

When the Nationalist Party assumed power in 1948, its apartheid policy heralded the introduction of restrictive measures that led to a reduction in pension expenditure on blacks, by limiting the number of black beneficiaries (Sagner, 2000). Race segregated policies provided an overall framework for the development of successive social age pension

legislation, up until 1993. Nonetheless, by 1993, on the eve of democracy, parity was achieved in the amount of the pension paid to beneficiaries in the different race groups, through the *Social Assistance Act* No. 59 of 1992 (Lund, 1999). Currently, the *Social Act* No. 13 of 2004 provides the legislative framework under which the social assistance grant programme is operated.

The old age grant provides a significant source of income to beneficiaries. It has a high take-up rate, especially in rural areas (Liebenberg & Tilley, 1998), and is seemingly well targeted to older persons (Case, 2001). The amount of the pension has been increased annually, in line with inflation; but numerous beneficiaries complain that the amount is not commensurate with escalating needs, especially those of beneficiaries burdened with the effects of HIV and AIDS, whose families and households make specific demands on their pension income (Ferreira, 1999).

Other legislation has also been available to address the needs of older persons historically. The *Aged Persons Act* No. 81 of 1967 provided for the protection and welfare of certain older and debilitated persons, the care of their interests, and the establishment of institutions to care for them. The act did not deviate from previous segregationist policy and legislation: in truth, it provided primarily for the white older population. Only a few residential care facilities, for example, were available for black older persons. However, the act was amended a number of times prior to 1994, in order to remove certain discriminatory provisions. These amendments culminated in the *Aged Persons Amendment Act* No.100 of 1998 (National Report on the status of older persons, 1994-2002). Nonetheless, the 1998 act continued to focus on residential care facilities, which accommodated a disproportionate number of white residents.

Then, new legislation was developed, over a protracted period, and a new act, the *Older Persons Act* No.13 of 2006, was finally adopted. Core objectives of the new act deal with issues relating to i) the protection of older persons' rights - as entrenched in the South African Constitution, including maintaining and protecting their rights as recipients of services; ii) combating elder abuse, and maintaining and promoting older persons' status, safety, security and dignity; and iii) the regulation and registration of residential care facilities. The protection of older persons' rights, as provided for in the act, supplements their rights protected under section 9 in the Bill of Rights of the Constitution of South Africa.

A particular strength of the act, relevant to this dissertation, is its acknowledgement of the right of older persons to receive information, education and counselling services on HIV and AIDS and on care for orphans. Moreover, the act promotes the provision of nutritionally balanced meals and medical care to needy older persons. In practice, several of the provisions, such as older persons' entitlement to dedicated medical care (e.g. geriatrics), are not being implemented, or at least not satisfactorily (see Benatar, 2004). The act makes no mention of the vulnerability of HIV infected older persons, nor the special support needs of these persons. More critically, it makes no provision for sustaining older persons' health so that they may continue to render care and support affected family members. The act merely represents the specific areas of responsibility that the Department of Social Development (DoSD) sees as its mandate; it does not cover the health, housing, transport, justice and other sectors, under which the rights, care and support needs of older persons fall equally. The legislation is therefore deficient in that it is not comprehensive.

The sectoral divide between the government ministries of social development and health continue to militate against integrated and comprehensive formal responses to the problems of older persons such as elder abuse (Ferreira & Lindgren, 2008). The *Aged Person Amendment Act* 100 of 1998 which provides among other things for "…the protection and welfare of older persons in certain institutions, for the accommodation and care of such persons in such institutions, for the payment of certain other allowances (subsidies) to meet older persons' needs…". Again, the act covers only the range of services provided by the social development ministry under its mandate (Ferreira & Lindgren, 2008). Provisions in the act cover, *inter alia*, the promotion and protection of older person's rights and the provision of programmes including community services for frail and homebound individuals.

There appears to be little harmonisation of programmes for older persons in South Africa, which continue to be operated independently, even within the same ministry. Little dialogue appears to take place between the social development and social security directorates within the Department of Social Development, and between this ministry and the health ministry regarding policy, programmes and services for older persons. This situation contradicts the stated mission of the DoSD, which it states is "to ensure the provision of comprehensive social protection services against vulnerability and poverty within the Constitutional and legislative framework, and to create an enabling environment … "(DoSD profile booklet, n.d.:1). Hence, what is lacking is a comprehensive approach to older persons' needs, to

ensure their well-being and inclusion in development initiatives. Thus, the development of a cross-cutting policy framework, possibly based within the DoSD, may be considered towards forging the co-ordination and monitoring of the development and implementation of interventions to meet older persons' needs.

3.5.4 Ministry of Health responses to older persons' needs

The health ministry has no dedicated policy pertaining to older persons; only a *National Health Act* (No. 61 of 2003). The legislation replaced the *Health Act* No. 63 of 1977. The new act provides a framework for legislation: it sets out broad legal and operational principles that are fleshed out in regulations. Some of the major principles of the new act are to establish a uniform health system; to restore dignity to citizens, and to provide free health care to those who cannot afford it. However, the act does not mention nor does it address the health needs of older persons. In general, the delivery of health services, as provided for in the act and policy, is guided by the philosophy of Primary Health Care (PHC) (see Chapter 2).

A key achievement of progressive implementation of PHC policy in South Africa is that people have far easier access to basic health care, owing to the removal of fees for services for certain vulnerable groups such as children under six years and pregnant women, among other measures. However, a move away from a hospital based system to a primary health care system has brought both achievements and problems, especially regarding provision of health care to older persons. Although older persons who are social pension beneficiaries are entitled to free health care at public health sector facilities (Ferreira & Kalula, 2007.), services such as geriatric clinics and community nursing at primary level were closed down after 1994 (see Benatar, 2004). The country has only eight registered geriatricians, who work at a tertiary level, to serve a population of 3.3 million persons age 60 years and over (Ferreira et al., 2007). Geriatrics is hardly included in the teaching curricula of any of the medical schools in South Africa. Ironically, the shift to PHC has neither eased the burden on hospitals at secondary level. Instead, admissions have increased phenomenally, by about 100 000 a year since 1994, mainly as a result of AIDS among other health problems (Department of Health, 2002).

Other ministries may have single mechanisms to address the needs of older persons. In 1998 the Transport Department launched its *Moving South Africa Strategy,* which represents a unique strategic framework for the improvement of passenger transport over a 20-year period. The new transport system is also directed specifically to historically disadvantaged people, among whom are elderly persons (South African Consulate, n.d.). The ministry has also developed and released a Transport Sector Strategic Plan on HIV and AIDS, the overarching objective of which is to "establish and maintain a healthy community and stable transportation sector by preventing and managing HIV and AIDS," but the plan does not mention older persons and their needs as a vulnerable group. Likewise, the housing ministry, a vital ministry in servicing the housing needs of older persons - especially the frail, developed a New Housing Policy and Strategy for South Africa in 1994, which has an all inclusive approach, critical for the sustainability and legitimacy of the housing delivery process. The policy specifically mentions special needs of certain groups in society such as the youth, disabled people and the elderly (New Housing Policy and Strategy for SA, 1994). A housing subsidy scheme established by the government makes special provision for older persons who are recipients of the OAP (New Housing Policy and Strategy for SA, 1994). However, implementation of policies of the two ministries to benefit older persons has been ineffectual. The majority of needy older persons are neither aware nor informed of the existence of such a scheme designed and operated to benefit them.

3.5.5 Ministerial responses to older persons affected by HIV and AIDS

Although AIDS is a major killer in South Africa (close to 336, 000 deaths in 2005 were associated with AIDS (MRC, 2006), the country has no national policy on HIV and AIDS that addresses the effects of the epidemics on older persons. The new National Strategic Plan (NSP, 2007-2011) makes no mention of older persons. No ministerial policies exist either on HIV and AIDS to address the effects of the epidemics on older persons *per se*. Only the Ministry of Social Development has developed a response, but which merely comprises interventions or programmes, such as strengthening home and community based care and support, incorporating gender and HIV and AIDS into all programmes, and providing support to orphaned and vulnerable children. The response makes no mention of older persons who care for persons infected with or affected by HIV and AIDS.

In 1992, at the time that the National Party government was gradually relinquishing power, a National AIDS Convention of South Africa (NACOSA) was convened, which brought together the African National Congress (ANC), the ANC-aligned United Democratic Front (UDF), and the National Party government's ministry of health to develop a comprehensive 1994 national AIDS plan. The plan estimated that by 2000, there would be between four and seven million HIV positive cases, with about 60 per cent of total deaths due to AIDS, if HIV prevention and control measures were not in place. In response, a National Strategic Plan (NSP) on HIV and AIDS (2000-2005) was developed. The NSP 2000-2005 emanated from the Operational Plan for Comprehensive HIV and AIDS Care, Management and Care 2003, and various programmes of the plan have guided the management of the epidemics in South Africa. However, the Operational Plan and both the old NSP 2000-2005 and the new NSP 2007-2011 strategic plans make no mention of older persons, either as infected or affected persons.

A review of national responses to the epidemics in South Africa shows sector specific policies relating to health, education, transport and housing. Beside these policies, are youth (18-35 years) oriented HIV/AIDS and STI programmes: e.g. voluntary counselling and testing (VCT) programmes, contraceptive programmes such as condom distribution, post exposure prophylaxis (PEP) programmes and syndromic management of sexually transmitted infections (STIs) programmes. A focus of the policies and programmes has been overwhelmingly on affected and infected children, and how to provide for future orphans as a result of AIDS (DoSD Strategic Plan, 2006/7-2009/10). Mention is made only in passing in some of the government ministries' legislation to older persons' situation, and then only in terms of the roles they assume as caregivers – to both adult children, and sick, vulnerable and/or orphaned grandchildren. Very little provision, if any, has been made in past and present national strategic plans (NSPs) and programmes for the support of older caregivers (NSP, 2005-07/2007-11) – either through information and education, in their roles as caregivers, or in their loss of support structures as their adult children succumb to the disease.

Nonetheless, the national education department's adult basic education and training (ABET) policy covers lifelong learning needs of adult persons, such as information and knowledge transfer on pressing national matters such as HIV and AIDS. In addition, the department has introduced a national law on HIV and AIDS, the *HIV and AIDS Act* No. 27 of 1996, for learners and educators in public schools, and students and educators in further education and

training institutions. Section 9.4 of the act acknowledges the valuable role played by grandparents and caregivers, and encourages their participation in the implementation of the policy, e.g. in parental guidance sessions. It also aims to make them aware of their role as sex educators and imparters of values at home.

On the other hand very little attention has been given in policies, even if noted in passing, to the significant contribution that older persons make in AIDS households towards sustaining the family unit and maintaining a family environment in which grandchildren without their parents may be nurtured and grow up (HAI, 2003a; Ferreira, 2006). South Africa's national policy response to the epidemics has not been different to that of other sub-Saharan African countries, in as far as including the needs of older persons, who are a care resource, is concerned.

According to South Africa's Constitution (1996), the country's citizens have the right to health care services under its Bill of Rights. Section 27(2) puts the onus on government to achieve the full realisation of this right. Therefore, by implication the government is constitutionally obligated and expected to implement a policy to address the HIV and AIDS epidemic. The South African HIV and AIDS strategic plans 2000-2005 and 2007-2011 are well developed documents. However, obstacles to implementation of what is on paper, are the contradictory or evasive public statements made by the country's President and the Minister of Health.

Most controversial has been former President Mbeki's challenge of the scientifically established causal link between the HI virus and AIDS (Swan, 2001; Mbali, 2002), and the scientifically proven effectiveness of anti-retroviral drugs in the management of AIDS, which the former health minister alleged are toxic and "kill." The negative media publicity of these recent controversial stances did grave damage to the credibility of the government and its policy response to HIV and AIDS. The resistance of the health minister to providing ARVs to prevent mother to child transmission (MTCT) of HIV, as well as her persistent emphasis on "nutrition" above ARV therapy (Geffen, 2006), further discredited the government's response to the epidemic. Although the government announced it would roll out ART at state facilities to prevent MTCT, it fought the national Treatment Action Campaign (TAC) and South African Medical Association (SAMA) in a constitutional court case, arguing that it is not constitutionally obliged to provide "toxic" ART. The ruling of the court was in favour of the

TAC and SAMA, and the South African government was ordered to provide treatment at public health care facilities (Moderator, 2008).

The disjuncture between what the government policy documents on the epidemics state and the utterances and actions of officials has caused uncertainty amongst health service providers and retarded progress in the fight against the disease. Caution among health service providers in public health establishments when treating PLWHA has been the order of the day (Smith, 2002), as the providers felt they were hamstrung and were afraid to contradict government rules. For example, when a medical doctor allowed a non-profit organisation to provide ARVs to rape survivors, the provincial health department applied stiff sanctions by suspending the official on grounds of misconduct and ultimately firing the official (Smith, 2002). With the later withdrawal of President Mbeki from the HIV and AIDS public debate, and his deputy-president's assumption of leadership against the epidemic, urgency in dealing with it was restored.

What is seemingly missing in government responses to the epidemic is the provision of tools to co-ordinate and integrate various ministerial responses. These responses include the co-ordination and implementation of different sectoral policies, strategic plans, programmes and legislation in a comprehensive response from government to older persons' support needs. The fragmented response and a lack of integration of older persons in the response to the epidemics remain an omission sorely in need of redress.

3.6 COMMUNITY RESPONSES TO HIV AND AIDS AND OLDER PERSONS IN SOUTH AFRICA

Despite the availability of a number of interventions for the management of the epidemics in South Africa by government ministries, implementation of programmes has been largely left to the non-profit organisation (NPO) sector. NPOs have interpreted their role in this regard as a link between hospital based care and home based care. In the majority of cases, where their credentials are approved – in accordance with the *Non Profit Organisation Act* No.71 of 1997, NPOs are permitted by law to carry out services in communities. The NPO Act mandates the Department of Social Development to contribute towards the creation of an enabling environment within which NPOs can operate and flourish. NPOs may be subsidised through allocations from government, but are expected to submit annual reports, showing a

history of good community service delivery and accessibility and affordability of the services. However, most NPOs are also reliant on funds generated externally, e.g. from the European Union, to support their operations (Peltzer et al., n.d.).

NPOs that serve and support older carers typically aim to empower them by working with them (as opposed to working for them) – for example, by engaging them in income generating projects, imparting life skills, educating them on their rights and how to exercise those rights, and educating them about HIV and AIDS. In addition, NPOs typically offer older carers useful skills training and knowledge needed to manage a PLWHA and OVC. They also offer them respite from the demands and routine nature of caregiving, by providing emotional and nutritional support, and practical advice on matters relating to caregiving (see Chapter 2). In this regard they honour and respect the rights that older persons have under the International Human Rights Declaration of 1948 - for example, the right to access to information and education.

3.6.1 Difficulties for NPOs to implement international instrument provisions

Non-profit organisations that provide support to households affected by HIV and AIDS rely largely on government and international donor agencies such as the Global AIDS Fund, ActionAid, European Union (EU), Oxfam and HelpAge International for information and financial support to sustain their operations and programmes (Jackson, 2002; Peltzer et al., n.d.). The NPOs are typically contracted by the government to deliver services at a community level. They tender to deliver specified services in a response to a call for tenders in the Government Gazette. If their tender is successful, they enter into contracts which stipulate the terms of reference and expected outcomes. The government provides funding and monitors the NPO's activities aimed at achieving agreed objectives within agreed time cycles.

Governments generally lack capacity to render community services, and as NPOs are knowledgeable about the support needs of the PLWHA and caregivers they work among, the government relies on them to provide the services. This reliance is particularly strong where responses are required to meet the needs of persons infected with HIV or affected by AIDS (Jackson, 2002). However, some researchers have pointed out that state agencies find it difficult to work with NPOs because of the NPOs' limited managerial capacity, and inability

to meet rigid agency accountability guidelines and costing such as in audited financial reports (Lenton et al., 2003; Mpanju-Shumbusho, 2003). In addition to partnership difficulties, NPOs tend to compete with one another for funds and credibility within the communities they serve, rather than forge alliances within the non-profit organization fraternity (International AIDS Alliance, 2002; Jackson, 2002) and rationalise employment of scarce resources. Another obstacle to the contributions that NPOs are able to make is low coverage. Drew and colleagues (1997) estimated that most home care programmes attain only about 1-2 per cent community coverage, and have poor referral of patients to other levels of care, because they are not well recognised, for example, by welfare workers or health care providers (Jackson, 2002; Akintola, 2004).

Non-profit organisations typically experience difficulty in obtaining funds from donor agencies. They will draft a funding proposal and submit it to an agency; the proposal will be assessed and approved for funding if it meets the agency's funding criteria. However, donor agencies often have inordinately complex application procedures and stringent requirements that are incompatible with the capacity and scope of NPOs (Jackson, 2002; Save the Children, 2005). An end result is that many NPOs are poorly managed, are unsustainable and are forced to close down.

Several studies have demonstrated NPOs' valuable involvement with PLWHA and their caregivers in AIDS care, treatment, literacy and education activities, and have noted the ability of the NPO personnel to anticipate the health and material needs of the community (Gilks et al., 1998; Blinkhoff et al., 1999; Oleja, 1999; Birdsall & Kelly, 2005). NPOs also provide non-formal education and raise awareness through less costly techniques such as songs, storytelling, community theatre and or drama - as a means of health education that is culturally acceptable to and effective in the community (WHO, 1978; Shaik & Hatcher, 2004). Non-formal methods of active learning are thus compatible with the general principles of Primary Health Care, such as community participation and appropriate techniques to deliver health messages (WHO, 1978).

3.7 SUMMARY OF THE REVIEW

The review of relevant instruments, legislation, policies and programmes covered the situation in several SSA countries, but focused largely on situations in South Africa. It was neither feasible nor indicated to attempt a fuller review of policies, strategic plans, programmes and legislation in regional countries in this chapter. The global and regional instruments and documents reviewed all highlight an acknowledgement of the burden of HIV and AIDS related caregiving on older persons in the 21st century - particularly in SSA. Gaps in and shortcomings of multi-sectoral responses to the effects of the epidemics at a national level have been identified, which relate specifically to the co-ordination, consultation and involvement of older persons. The identification of such gaps and shortcomings will serve to inform the development of a policy framework for addressing the needs of older persons affected by HIV and AIDS later in this dissertation.

3.7.1 International response frameworks

International instruments such as the Madrid International Plan of Action on Ageing (UN, 2002b) acknowledge the challenges faced by numerous older persons, especially in developing countries, and urge governments to introduce policies that make provision for in-kind support, health care and loans to older caregivers to assist them in meeting their household needs. These recommendations call for governments to do more than what they do at present, given the added problems that many older persons currently face, such as caring for sick adult children and OVC as a result of AIDS. Although the South African government is a signatory to MIPAA, it has thus far not taken steps to ensure that AIDS treatment and support strategies and programmes address the needs of older persons affected by the disease. On the other hand several NPOs have designed and implemented programmes and interventions to support these persons. Nonetheless, review and appraisal of progress in the implementation of MIPAA globally is under way at present (Sidorenko, 2004) and outcomes of the review may indicate the stage of progress in this regard in SSA countries. Similarly, recommendations in the AU Policy Framework and Plan of Action on Ageing (AU, 2003), to which the South African government is also a signatory, such as ensuring that older persons' needs and rights are integrated in all existing and new policies in all sectors, has not been realised. In short: older persons' needs, especially relating to HIV and AIDS, are not being addressed adequately, if indeed at all, in any policy sector in South Africa.

3.7.2 Regional and national responses

Regional instruments such as the African Consensus and Plan of Action to Overcome HIV and AIDS (Africa Policy E-Journal; 2000), and the AU Policy Framework and Plan of Action on Ageing (AU, 2003) provide concrete steps to be taken to support older caregivers. Among the steps recommended are the provision of support for caregivers and opportunities for older persons' participation in development initiatives, to enable them to become full allies in the fight against the epidemics. Most countries in the sub-region (SSA) have developed policies or strategic plans in response to the epidemics. Some countries that have shown the political will to fight the epidemics, such as Uganda, have managed to turn their country's epidemic around. However, the majority of the policies or strategic plans do not include older persons or their representative organisations as important role players in the fight. There is neither any evidence to indicate that the commitments made in the documents have been implemented in the majority of the countries, including South Africa.

3.7.3 South African government responses

The review has highlighted a lack of, or ineffective responses to the support needs of affected older caregivers in South Africa. Multi-sectoral responses have been lacking, in particular, through a lack of co-ordination of response programmes of the health and social development ministries, and older persons' non-integration in programmes. Ferreira and Lindgren (2008: 91) have pointed to fragmentation in sectoral policies and programmes: "[while]…the social development ministry is tasked with the subsidization of frail care, which is primarily a health matter; nursing regulations are determined by the health ministry, while monitoring of facilities should be done jointly." A lack of consultation with older persons, or at least organisational representation of their interests in the development of critical instruments such as the national strategic plan on HIV and AIDS, is another key gap in the formulation of national responses to older persons' support needs.

A failure to co-ordinate HIV and AIDS responses within a well developed policy framework will continue to cause older caregivers' issues to be overlooked in policy responses. Joubert and colleagues (2002) note that this oversight constitute(s) an undermining of older persons' human rights. Thus, a policy framework that provides for the inclusion of a range of role players, from government, non-profit organisations, religious bodies and business, can

provide for the development of an appropriate, integrated comprehensive response to older carers' needs.

Provision of support to meet older carers needs, needs to incorporate an element of Primary Health Care: that of advancing health and well-being into old age. The World Health Organization's active ageing policy framework (WHO, 2002c) calls for the development of health care systems that are responsive to the needs of ageing populations. Such systems should be aimed at enhancing the capacity of the primary health-care sector to respond to older persons' health care needs at a local level and to do so appropriately. The Madrid Plan (UN, 2002b) recommends that health care services include special training of health personnel and that facilities meet the special and specific health care needs of the older population, such as the management of chronic illnesses.

South Africa's public health system is under severe strain to meet multiple demands made on its limited resources. A myriad of obstacles limit equitable provision of health care to older persons, such as limited staff trained in geriatric care, the brain drain of qualified and specialist staff, a shortage of drugs and industrial action by health care providers. Therefore, although government ministries have formulated progressive policies and legislation to meet older persons' needs, the task now is the implementation of the provisions through programmes to a satisfactory level.

Finally, some progress has been made in South Africa in reforming legislation, such as the *Older Persons' Act*. The new legislation is designed to address the needs of all older persons equitably. Such progress has been achieved since 1994, through the new political dispensation, directed in particular at closing disparities in social security (OAP) among older persons. However, much more remains to be done in involving older persons in the formulation of formal responses to their needs in general. Indeed, a main obstacle to the implementation of the provisions of international instruments, and the formulation of national policies and strategic plans is the fact that financial resources are required that the government may lack, forcing it to be selective in the allocation of its limited resources.

3.8 TOWARDS AN APPROPRIATE POLICY FRAMEWORK

A number of international, regional and national instruments are thus available to guide the development and implementation of policy and programmatic responses to the needs of older persons affected by HIV and AIDS, but numerous gaps remain in national policies that mitigate against a comprehensive and inclusive response. Mechanisms and frameworks are needed to address the gaps in order to benefit of older persons. The construction of an evidence based policy framework will be a valuable contribution in this regard. Such a framework should provide for: i) The involvement of older persons or their representative organisations in the design of responses; ii) the co-ordination of responses of different government departments, iii) sensitivity to the gendered nature of caregiving; iv) acknowledgement of disparities in socio-economic status and difficulties of caregiving for older carers in rural and urban settings; v) meeting the health care needs of older carers themselves; vi) training health care personnel in the health care needs of older clients at district level; and vii) taking cognisance of older persons' rights as caregivers and integrating their contributions in the development of interventions. In this dissertation, I attempt to bridge such gaps by developing a policy framework that is informed by evidence from an empirical study to be conducted. The framework will lie at the intersection of various socio-economic, development and health care needs of affected older persons. Such a policy framework may serve to bridge and fill gaps in future policy development, and to inform policy and programme development and implementation.

CHAPTER FOUR: RESEARCH METHODOLOGY

4.1 INTRODUCTION

The research design and research methods used in the empirical study are described in this chapter. A mixed-methods approach was employed, which included quantitative and qualitative research techniques. Both methodologies have particular strengths and weaknesses, but when used together, the weaknesses of one method could be mitigated by the strengths of the other. Quantitative and qualitative research techniques can thus be employed compatibly in the same study (Patton, 1990; Newman & Benz, 1998). Given the nature of the research questions of the empirical study in this thesis, the employment of a single quantitative or qualitative data collection technique on its own would not have enabled me to capture the complex and multiple dimensions of the impact of HIV and AIDS on older persons' households and older carers. Thus, the employment of a mixed-methods approach, in which the two research methods were combined, was indicated and constituted an innovative research approach in this problem area.

4.1.1 Quantitative and qualitative research

4.1.1.1 *Quantitative research methods*

Quantitative research typically involves numerous variables and treatments, such as factorial designs and repeated measure designs. The designs can involve elaborate structural equation models that incorporate causal paths and the identification of the collective strength of multiple variables (Creswell, 2003). A single quantitative enquiry technique, however, is to be employed in the present study, namely a survey. A survey is typically a cross-sectional (but may be a longitudinal) data collection technique in which a pre-constructed questionnaire is used in structured interviews to collect data. The quantitative nature of a survey is generally reliant on the recruitment of a representative sample of the population of interest. The requirement of a randomly selected sample is to be able to generalise findings from the sample to the study population, so that inferences may be made about certain characteristics, attitudes, and/or behaviour of the population of interest (Babbie, 1990; Fowler, 2002).

Fink (1995) identifies four types of quantitative survey: i) Self-administered questionnaire; ii) face to face interviews; iii) structured record reviews – to collect financial, medical, or school information; and iv) structured observations. In addition, web-based or internet and telephone surveys may be employed as a survey data collection technique (Nesbary, 2000). In the present study, the data will be collected at a single point in time (the study design is thus cross-sectional), using a pre-constructed questionnaire administered in face-to-face interviews.

Quantitative data are measurable units of information, and are amenable to statistical manipulation through the application of different scientific techniques. A main purpose of quantitative data is to define and measure the magnitude of the problem under investigation. However, the data are limited in that they do not describe or capture human aspects of the problem, such as actors' perceptions, feelings and views (Creswell, 2003).

Hence, a limitation of quantitative research methodology, and the use of a survey technique in the present survey, is that the data collected do not allow sufficiently for understanding complex issues – such as the effects of HIV and AIDS on older carers, and neither have the flexibility to explore sensitive issues (Griffin, 1986; Schoepf, 1991). To compensate for this weakness, as will be done in the present study, qualitative research techniques may be used in conjunction with, and complementary to a quantitative research technique – in the present case, a survey.

4.1.1.2 *Qualitative research methods*

Qualitative research techniques are mainly used for exploratory purposes, typically to explore a topic when little is known about the variables and theory base. Morse (1991:120) suggests that:

Characteristics of a qualitative research problem are: (i) the concept is 'immature' due to a conspicuous lack of theory and previous research; (ii) a notion that the available theory may be inaccurate, inappropriate, incorrect, or biased; (iii) a need exists to explore and describe the phenomena and to develop theory; or (iv) the nature of the phenomenon may not be suited to quantitative measures.

Different techniques are employed in a qualitative research approach to understand a phenomenon. In this study, the qualitative techniques used were case studies and key informant interviews. *Case studies* are used where a researcher explores an event, a process, or one or more individuals in-depth over a period of time; the researcher collects detailed information using a variety of qualitative data collection techniques (Stakes, 1995). The key informants technique involved obtaining information from knowledgeable persons for example NPO managers and government officials. In the present study, unstructured in-depth interviews were conducted with purposive samples of older respondents, and government and NPO representatives. The interviews with the older respondents were written up as case studies.

Unstructured interviewing, as a qualitative research technique, is well suited to the identification and description of experiential issues and daily activities (Gergen, 1988; Mitchell & Jolly, 1996; Hudelson, 1996; Mayan, 2001; Creswell, 2003). The technique is premised on an understanding that respondents are not mere objects to be counted, or having measurable characteristics, but rather are human beings who are in constant interaction with their environment and make sense of their experiences in that environment. Bowling (1997) suggests that such techniques are better able to provide insight into complex issues, and are more useful in studying new topics – or exploring topics on which little is known, than quantitative research techniques.

Qualitative data typically have a richness and a complexity that are lacking in quantitative data. Indeed, qualitative research approaches, and the data they elicit, are less bounded by a researcher's assumptions, and are more likely to be sensitive to unexpected findings (House, 1994). Probability statistics, derived through quantitative research, are numerous on a number of social issues, including health – for instance, but tell nothing about the experience of the subjects that make up the numbers; thus, only a fragment of knowledge is achieved.

Qualitative research has limitations, however. One limitation is a dependence on a conceptual framework to guide the inquiry on the issues to be examined. A qualitative study needs to indicate moreover how or where a researcher positions him-/herself; biases in the investigation and the data collected may stem from the researcher's social class or cultural position (Creswell, 2003; Miles & Huberman, 1984; Strauss, 1987). An additional concern – certainly for quantitative research oriented investigators, may be a lack of systematic

procedure, and problems of reliability and validity, as no tests are carried out on qualitative research data. (Mcqueen, 1992; Hardon. et al., 1995; Baum & Nesselhof, 1998). However, in their own right, qualitative data offer an appropriate source for deriving meaningful interpretations of subjects' experience (Hudelson, 1996; Schurink, 1998; Mayan, 2001).

4.1.1.3 *A mixed-methods approach*

Given the limitations of both quantitative and qualitative research methods, when used on their own, for achieving an in-depth understanding of a complex phenomenon, a decision was taken in the present study to employ a mixed-methods approach. The approach, which uses a combination of qualitative and quantitative methods to investigate a problem, would provide for a validation of the data, and findings of the analyses of the data elicited through the employment of multiple techniques. Qualitative and quantitative research methods are located at opposite ends of a continuum of methodological approaches, and each has its own principles and assumptions. The advantages and disadvantages in the use of a particular technique – and a particular approach – in the study were weighed in terms of the study's objectives. The employment of a mixed-methods approach would thus help to compensate for the weaknesses of a particular technique with the strengths of another (Creswell, 2003), and so strengthen the study findings and provide an improved understanding of the problem overall.

Nonetheless, the logic of incorporating qualitative research in the research design of the present study was to gain an understanding of caregiving and the support needs of older caregivers specifically. The qualitative methods would allow the researcher to probe the respondents' responses, and would facilitate the collection of narratives about the respondents' needs, experiences, of caregiving and knowledge and beliefs about HIV and AIDS. Unstructured questions would encourage a conversational approach in the interviews – although focused on a specific set of issues. The data elicited through the employment of the multiple techniques would later be triangulated, which would further help to offset inherent weaknesses of the methods and help to correlate the findings. Triangulation is discussed more fully later.

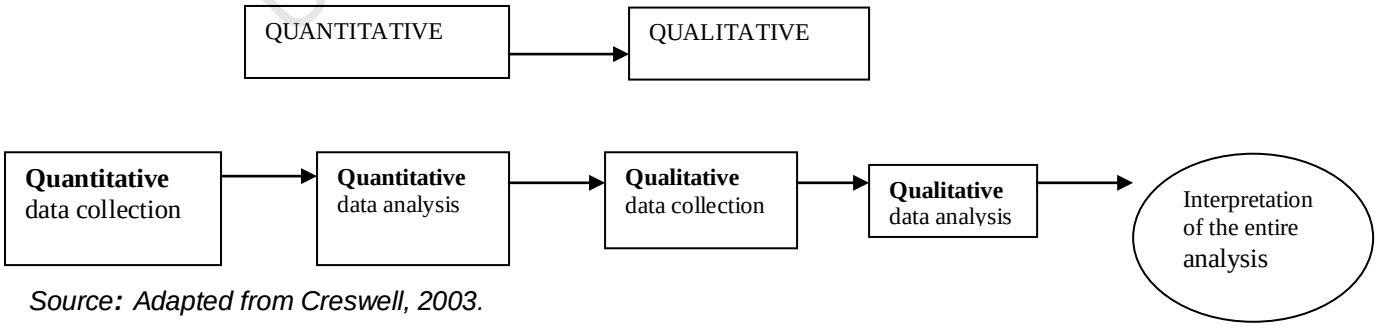
4.2 RESEARCH DESIGN

The research design employed in the present study is described below. No single research design can be identified as the most appropriate design for investigations of the problem of HIV and AIDS and its effects on older carers (see e.g. Fisher & Foreit, 2002). Nor is the employment of a particular research method, or the use of a particular research design of concern in this study, but rather how to collect data most effectively to serve and meet the study's objectives. The research design needed to be "exploratory-descriptive," and a decision was taken to employ a cross-sectional survey technique in conjunction with case studies and key informant interviews. The data from all sources were then triangulated.

A mixed-methods approach was used in the study. The approach helped the researcher to quantify the extent of the problem (older caregivers' experiences) and provided simultaneously for an understanding of the human experience in this case. The use of multiple methods, or the employment of several data collection techniques thus provided a comprehensive view and understanding of the older carers' situations and experiences.

The specific design approach employed in the study is referred to as a sequential procedure design (Creswell, 2003), and is shown graphically below. When carried out, the procedure enables the researcher to confirm, cross-validate and corroborate findings within a single study (Creswell, 2003; Poundstone et al., 2004). (See Figure 4.1.)

Figure 4.1: Sequential triangulation design



Source: Adapted from Creswell, 2003.

4.2.1 The survey

Kerlinger (1964) suggests that survey research is characterised by the collection of data from a sample of a population of interest, to assess the relative prevalence, distribution and interrelationships of naturally occurring phenomena in that population. Bryman (1989:104) argues for a formal definition of a survey, as "…entail[ing] the collection of data on a number of units and usually at a single juncture in time, with a view to collecting systematically a body quantifiable data in respect of a number of variables which are then examined to discern patterns of association." Bryman's emphasis is on survey research being conducted to provide a quantitative description of the individuals or other units concerned in a study. His emphasis on the quantification of variables and on sampling from known populations shows how survey researchers may share a similar scientific view of the nature of the research task from that adopted by researchers using qualitative research. Bryman's definition is applied in this thesis, for the empirical study, but the survey data are later complemented with qualitative research data.

4.2.1.1 *The study population*

The study population for the study consisted of all older persons (male and female) age 50 years and over who cared for adult children living with HIV and AIDS and grandchildren (who might or might not have been infected with the virus), who lived in households in urban settings or non-urban settings in three provinces of South Africa: the Eastern Cape (EC), Kwa-Zulu Natal (KZN) and the Western Cape (WC). The households appeared on the lists of clients of non-profit organisations (NPOs) – NGOs, CBOs and FBOs - that supported households in those areas. A database of NPOs in the provinces was obtained from the provincial departments of Health and/or Social Development.

The areas were delimited according to Statistics South Africa (Stats SA, 2001) census enumerator areas. The three provinces were selected due to the high prevalence of HIV infection in KwaZulu-Natal; the relative poverty and deprivation in the Eastern Cape – with an economic growth rate of 1.2 per cent; and the relatively strong economic growth rate of 4.6 per cent and the extent of established health services in the Western Cape (Stats SA, 2004). In the Department of Health's ante-natal seroprevalence survey, KZN was recorded as having the highest prevalence rate of HIV infection (37.5 %) (Makubalo et al., 2004).

A lower cut-off age of 50 years was set for the study, in line with the World Health Organization's Minimum Data Set on Ageing and Older Persons in sub-Saharan Africa (Ferreira & Kowal, 2006), rather than the internationally applied lower cut-off age of 60 years (UN, 2007). Justification for lowering the cut-off age was based on three considerations: i) Persons in the 50–59 year age group will be the next generation of older persons, and future resource requirements for planning purposes may be estimated from the number and situation of affected persons in this age category. Such estimates would include a projected demand for social security, health care and institutional care. ii) Within the African context, persons falling in this age category are traditionally regarded as old and responded to accordingly (WHO, 2001). iii) Research on older carers to PLWHA and OVC conducted by Ferreira et al. (2001) in the Western Cape Province found a need to lower the cut-off age to 50 years in order to recruit a sufficiently large sample of carers.

4.2.1.2 *The survey sampling procedure*

The sampling unit was a household in which an older carer co-resided with PLWHA and/or OVC. A sample size of 240 such households was determined, drawn from the three provinces, intended to be divided equally between urban and non-urban areas. However, it was not possible to recruit equal numbers of participants in urban and non-urban areas, as some sampled households did not meet the sample's inclusion criteria.

This figure was decided upon due to resource and time constraints, and on the basis that the extent of caregiving by older persons is unknown in the three provinces and in South Africa as a whole. However, a prevalence of 50 per cent caregiving among the respondents was assumed and a sample size of 305 subjects was accepted for the study which would allow a detection of 8 per cent change in the caregiving (at 80 per cent power and 5 per cent level of significance). The sample size was therefore increased from 240 to 305 to accommodate a 10 per cent refusal rate.

A multilevel sampling technique was used to draw a sample from the lists of NPO client households. The number of NPOs providing services to affected households identified in the delineated study sites in the three provinces were as follows: Eastern Cape: 131; Kwa-Zulu-Natal: 106; and Western Cape: 38. It was estimated that each NPO cares for between 100 and 450 households. The services they provide include imparting HIV and AIDS information and

education, developing income generation opportunities, addressing human rights issues, and counseling clients. Information on the exact proportion of households benefiting from the NPO services could not be obtained.

Nonetheless, an estimate of the relative proportions of older persons in the three provinces was gauged as follows: A household survey conducted in 2007 by STATSSA showed that 38.2 per cent of all old age grants were paid to beneficiaries in the Eastern Cape, with 46.4 per cent in KwaZulu-Natal and 15.3 per cent in the Western Cape (STATSSA, 2007). These beneficiaries would receive free primary health care at specific levels of the public health system, such as the district level.

A database of all registered NPOs in the country was obtained from the national Department of Social Development (DoSD), and an alphabetical list drawn up of all NPOs serving clients affected by HIV and AIDS in the three study provinces. These NPOs were then allotted numbers in sequential order, by province. Pieces of papers with these numbers on them were placed in a container which was shaken and the researcher drew papers from the container, one by one, until seven numbers representing NPOs were identified. The 15 households were then selected systematically, instead of randomly, from the client list of these seven NPOs, to avoid fieldworkers visiting households in close proximity to one another and thus not risk raising community members' suspicions about HIV and AIDS affected households.

The survey sample was recruited in the following way: Potential respondents who were aged 50 years or over and a primary caregiver in a listed, affected household were invited to participate in the study, The aims of the study were explained to them fully and what would be required of them if willing to participate in the study. They were then required to sign an informed consent form (Annexure 1); if unable to read and write, the contents of the form were explained to them fully and they were able to give verbal consent to the fieldworker.

Substitution of households was permitted in cases of refusal and absenteeism. Substituted households were identical to those originally selected: i.e. the house was in the same district or area and an older carer resided in the house. Similarly, NPOs that did not provide support to older carers, such as advice, counseling, food parcels and skills development, were substituted with an NPO that did render these services.

The sampling was thus stratified by province and the sample selection based on a cluster sampling technique (Kish, 1965, 1987; Babbie, 2001). The sampling procedure SURVEYSELECT (SAS V8, 2004) was used, which selects the sample and calculates the sampling probabilities from which the sampling weights are calculated.

4.2.1.3 *The survey instrument*

A semi-structured data collection instrument was specially designed for use in the survey (Annexure 2). The instrument included both fixed-response and open-ended items, and incorporated skip patterns. Thus, while the tool was aimed primarily at capturing quantifiable data, to describe the situations, problems and support needs of older persons who provide care to adult children living with HIV and AIDS and affected grandchildren, it also provided for the capture of narrative responses.

The survey instrument was constructed in two parts: Part 1 provided for the gathering of quantitative data and comprised fixed-response items, in which responses could be measured using nominal scales with dichotomous variables such as yes =1 and no = 2, and ordinal (Likert) scales with ordinal variables such as 1 = excellent, 2 = good, 3 = fair, 4 = poor. This part was divided into six sections: i) A cover page for household and respondent identification purposes: ii) Section 1 for demographic and household data; iii) Section 2 for information on the respondent's health status; iv) Section 3 for assessing the respondent's knowledge and awareness of HIV and AIDS; v) Section 4 on caregiving to persons living with the disease; vi) Section 5 on caregiving to orphaned/grandchildren; and vii) Section 6 on support received from the government and other community structures such as churches.

Part 2 provided for the collection of open-ended (narrative) responses and comprised eight items. Responses to these items provided information on the respondent's own assessment of the most critical needs or challenges in a specific problem area (Burman, 1994). These responses were recorded verbatim. Based on the nature of these responses, the researcher later identified respondents and households for participation in a follow-up, in-depth interviewing study, to produce case studies.

4.2.2 Case study interviews

A case study may be defined by a particular interest in individual cases and not by the method of inquiry used (Stake, in Denzin & Lincoln, 2003). The purpose of gathering data from a "case," or individual, is to understand what is specific and what is different (about that case), and what can be learned about or from the case. In general, case studies are used to gather in-depth and intensive information from individuals whose situations or circumstances may be of particular interest in a study. Case studies can be of an "intrinsic" or "instrumental" nature. In an intrinsic case study, a small group of individuals is studied, while in an instrumental case study, a single case is examined (Welman & Kruger, 2002). An intrinsic case study is directed at understanding the uniqueness and idiosyncrasy of a particular case in all its complexity (Welman & Kruger, 2002). The investigator describes or records what and why the person says, or why he/she behaves in a particular way (Rosnow & Rosenthal, 1996). Such a study can provide a holistic, historical picture of an individual and/or her/his household's situation, such as how the household copes with the impact of HIV and AIDS. In an instrumental case study, a particular case is examined: not for its own sake, but mainly to provide insight into an issue, or to draw a generalisation (Denzin & Lincoln, 2003); the actual "case" is of secondary interest.

Case studies are used in diverse areas, such as in policy making studies, psychology, health research, and any situation that calls for descriptive information such as the depiction of a subject's specific situation (Bromley, 1986). The studies "provide more valid portrayals, better bases for personal understanding of what is going on, and solid grounds for considering action" (Stakes, 1981:32).

In the present study, an intrinsic case study technique was employed. Ten case studies of older carers were conducted in the Western Cape Province only, and not in the other two provinces, for logistical reasons. The ten households were purposively selected (Hammersley, Gomm & Foster, 2000) from the 305 completed questionnaires, and revisited by the researcher within one to three months of the survey interview. The selection of respondents for this study was based on "unexpected" or unanticipated responses given in the survey interviews, which were indicative of their particular situation and of interest to the researcher (Carroll & Johnson, 1990). Examples of "unexpected" responses were beliefs that AIDS could be cured and that HIV is a demon that can only God can remove. Such responses, of a

religious nature, were viewed as unexpected in that the older carers had already been exposed to considerable scientific information and education from the NPO to which they belonged, which seemingly contradicted the knowledge they had about AIDS.

The questions for the case studies, or in-depth interviews, were developed from a preliminary analysis of data recorded in the survey questionnaires. The researcher conducted the interviews himself with the use of a semi-structured interview schedule constructed from these items (Annexure 4).

A case study technique was used to collect the qualitative data, rather than another technique such as focus group discussions. Use of the case study approach was informed by a need to protect respondents from possible embarrassment about their family situation. More importantly, the sensitivity of HIV and AIDS and risk of stigmatisation would mean that the topic would not lend itself to frank discussion. The case study technique allowed the respondents to speak freely in the privacy of their home.

4.2.3 Key informant interviews

Key informants are individuals who are presumed to be knowledgeable about an issue under investigation (Hardon et al., 1995). They may be representatives of institutions or organisations, or people who are accorded special status within a community, such as community leaders, or older people (Kumar, 1986). Advantages of interviewing a key informant are the structured contact that the interview provides and an opportunity to gather detailed information (Doll-Yogerst, n.d.). The technique is particularly useful in the gathering of information to inform policy review and reform (Morton, 2002; USAID, 1996). Other advantages of key informant interviewing are that the information is provided directly by knowledgeable persons; the interviews afford flexibility for the researcher to explore new ideas and issues not anticipated during planning; and the interviews have a low cost. However, a disadvantage of the technique may be bias in the information provided, and to this end the researcher must attempt to ensure that a balance of opinions and views is achieved, through judicious selection of the informants (Kumar, 1986).

Nine key informants, six in government and three at non-profit organisations, were interviewed in the study. One NPO manager was selected in each province with an aim to balance the views, perceptions and opinion of the managers on government policies and

programmes, with those of two senior managers in the departments of Social Development and Health in each province, across the provinces, giving a total of nine key informants. The purpose was to learn about the content and implementation of policies, through strategies and programmes, relevant to the inquiry, and whether the policies are responsive to the needs of older carers – from the informants' perspective, or in their experience or opinion. The semi-structured interviews were guided by a schedule of issues to be discussed (Annexure 5). The researcher framed questions in the interview guide spontaneously, to probe for specific information, and kept notes of responses that were elaborated on later (Kumar, 1986; USAID, 1996).

Interviews were conducted with 1) representatives of government health and social development departments, and 2) NPO managers – in each of the three provinces. The informants were officials presumed knowledgeable about available relevant policies, strategic plans and programmes pertaining to HIV and AIDS and older persons. The key informants selected for interviews is shown in Figure 4.2 below.

Figure 4.2: Profile of the key informants interviewed

	Department/Organisation	Portfolio/Area of activity	Designation
	Government informants		
1	Department of health (EC province)	HIV/AIDS directorate	Director
2	Department of Social Development (EC province)	Social Services directorate	Director
3	Department of health (KZN province)	HIV/AIDS directorate	Manager
4	Department of health (WC province)	HIV/AIDS directorate	Manager
5	Department of Social Development (WC province)	Social Services directorate	Manager
6	Department of Social Development (KZN province)	Social Services directorate	Manager/Director
	NPO informants		
7	Jersey Farm Older Person Support (EC)	HIV/AIDS support	Manager
8	Nobuhle Community Project (KZN province)	HIV/AIDS support and home based care	Manager/Co-ordinator
9	Grandmothers Against Poverty and AIDS (WC province)	HIV/AIDS support and income generation	Director/Co-ordinator

4. 3 DATA COLLECTION

4.3.1 Survey data collection

All items in the survey instrument were deemed relevant to an understanding of the nature, extent and problems of caregiving relating to HIV and AIDS. The instrument was developed by the researcher in English, and translated into the relevant languages of the study population by first-language speakers, all of whom had a tertiary qualification in a specific language. The instruments were then back translated into English by a researcher not associated with the study. The instrument was administered in face-to-face interviews conducted in the respondents' homes – as far as possible in a private place. The three master's students used were versed in the three African languages namely isiZulu, isiXhosa and Afrikaans. They were also fluent in English. They were also contracted to validate the translation of the questionnaire through back translation and standardisation to remove ambiguities.

The questionnaires were administered in a respondent's preferred language. The duration of the interviews was estimated to be less than 60 minutes. Entry to the households was facilitated by the NPO or CBO from whose client list a household was selected. Specially trained fieldworkers (see Section 4.3.1.1 below) were accompanied to the house by a home-based carer engaged by the NPO (but who was not present during the interview). The fieldworkers were deployed to areas where they were not known. After each interview, a fieldworker leaved behind a pamphlet with the respondent that had a list of relevant resources in the area from which the respondent could seek assistance, if he/she so wished (Annexure 3).

If no participant (an older carer) was found at a household visited by the fieldworker on three visits at different times on the same day (morning; midday and late afternoon), a "non-response" was recorded on the questionnaire. Such households were thereupon substituted with another household that met the study selection criteria.

4.3.1.1 *Recruitment and training of fieldworkers*

Twelve fieldworkers were recruited and trained to gather data for the study: four in each province. All had at least a Grade 12 level of education (they had matriculated). They had

special training on i) knowledge about HIV and AIDS; ii) a brief history and the current state of the epidemic in South Africa; and iii) sexually transmitted infections (STIs) and other modes of transmission of the HI virus. The fieldworkers were trained in developing rapport with respondents; how to interview an older person (e.g. speak slowly, clearly and loud enough); reading the consent form to the respondents; administering the questionnaires; and on the ethics of the study, especially relating to the sensitive issue of HIV and AIDS and associated stigma. Role play was used to model real interview situations; the fieldworkers took turns to interview one another during training, observed and redirected by the researcher. A risk of fieldworkers misinterpreting the meaning of an item was minimised through the role play; they were guided in reaching a common understanding of what an item sought to elicit or measure. The fieldworkers all belonged to the same ethnic group as the respondents in the different provinces.

All interviewers were trained extensively in interviewing and the interview process. "Real" interview settings were simulated in which the interviewers carried out role play by interviewing one another. Information gathered from the mock interviews was checked for completeness before the start of the field work; the data from these interviews were then discarded and not included therefore with the survey data.

Supervisors were trained in monitoring the field work and checking completed questionnaires when returned from the field. Where information was missing, interviewers were sent back to a respondent to collect the data**.**

4.3.1.2 *Field set-up logistics*

Prior to conducting the fieldwork, telephonic and face-to-face consultation was carried out by the researcher with the manager or co-ordinator of an NPO/CBO/FBO. An appointment was made with the relevant person at the organisation for a meeting, during which the researcher explained the nature and purpose of the study fully.

4.3.1.3 *Pre-testing of the survey questionnaire*

The survey instrument (Annexure 2) was pre-tested on five older persons who resided in the researcher's neighbourhood, to test the wording and clarity of the items (to eliminate unclear or ambiguous phrasing) and their logical sequence in the instrument. The instrument was subsequently refined accordingly.

4.3.1.4 *Piloting of the survey questionnaire*

A pilot study was conducted by the researcher on a 5 per cent sample (n =10 households) using the survey instrument (Annexure 2). Minor adjustments were made to the instrument after completion of the pilot study. The informed consent form was "tested" in the pilot study as well and found to be satisfactory. The duration of interviews ranged between 30 and 45 minutes. The pilot study questionnaires were not included in the survey sample. Problems of readability and flow of the questionnaire were checked during the pilot study.

4.3.1.5 *Problems encountered during fieldwork*

Minor problems were encountered during the fieldwork, which were dealt with in the following ways: As the study inquired about older carers' support needs, and what respondents' perceptions were of what the government should provide for them, the interviews ran the risk of creating expectations in the respondents that could not be met by the study in the short term. This risk was addressed in the information/consent form, where the purpose of the study and expected outcomes were outlined. Where it became apparent that expectations had been raised in a respondent, the fieldworkers were instructed to refer the respondent to the signed informed consent form. The fieldworkers were also trained to manage situations such as emotional outbursts. However, no untoward problems were reported regarding any of the above.

Some difficulty was experienced though in certain fieldworkers not starting fieldwork on some days on time, and some fieldworkers lost study materials which needed to be replaced. Some fieldworkers reported a shortage of money for transport. Finally, inclement weather in some settings delayed the progress of fieldwork. The latter problems were however of a logistical nature and were managed satisfactorily by the researcher.

Where fieldworkers experienced operational problem(s) in the field, the following procedures were followed:

4.3.1.6 *Recording of responses*

In general, all responses and their corresponding codes were recorded on the questionnaire (Annexure 2) by marking an X, except where a question had to be skipped according to skip pattern instructions. A "no response" option was deliberately excluded to discourage interviewers from taking an easy response option.

4.3.1.7 *Pre-coded questions*

Most questionnaire items were pre-coded and only one response was provided for each item. In some items an "Other" option was provided. In these cases, the interviewer was required to write out the respondent's full response, verbatim as far as possible. The formatting of items is shown in the questionnaire in Annexure 2.

4.3.2 Case study data collection

The interview schedule employed to gather information from selected respondents in the unstructured, in-depth interviews, towards compiling the case studies, comprised open ended questions (Annexure 4). The instrument was administered by the researcher, who recorded the responses, or narratives manually, as far as possible verbatim, on the schedule. Where a respondent gave consent, an interview was audio-recorded.

4.3.3 Data collection during interviews with the key informants

Data were collected from the key informants by the researcher using the specially constructed interview schedules: Annexure 5 in the case of government informants and Annexure 6 in the case of the NPO informants. All interviews were conducted in English. The informants' responses to the set of topics for discussion were recorded on the schedules, as far as possible verbatim. Of the nine interviews, five were audio-recorded with the informants' consent. In general, the informants were co-operative and discussion flowed freely. However, some explained that they had only been appointed to their position recently, and were not as knowledgeable about the topic of discussion as they would like to be, but were nevertheless willing to assist as far as they could. The data collected primarily related to the informants' views on and understanding of the government's management of HIV and AIDS, and policy intervention, or lack thereof, as it related to older carers' support needs.

4.4. SEQUENCE OF THE DATA COLLECTION

The collection of qualitative data followed on the completion of the survey and preliminary analysis of the data. The survey data highlighted the nature and magnitude of problems older carers experienced, and this information helped the researcher to develop items to guide data collection in the qualitative follow-up study. Qualitative data were not collected prior to the survey for the following reasons: i) Knowledge in the subject area is fairly expansive and

additional exploration at that stage was considered not warranted. Pre-survey exploration would indeed have been carried out if little was known in the area of investigation, as argued by Creswell (2003). ii) First-hand interaction of the researcher with older carers while employed as a researcher at the Human Sciences Research Council had equipped him with an understanding of older carers' burden. iii) The identification of topics for follow-up in the qualitative in-depth study was based on an analysis of the survey data, and collection of qualitative data after completion of the survey is thus self-explanatory.

4.5 DATA MANAGEMENT

4.5.1 Collation of the completed questionnaires

One of the four fieldworkers in each province was designated as a supervisor, and was responsible for the collection and enumeration of all completed questionnaires. The three supervisors checked the questionnaires on the day they were administered, to ensure identification and rectification of errors in the field immediately. Each checked questionnaire was reviewed with the responsible fieldworker. If a supervisor was not satisfied with a completed questionnaire, the fieldworker was required to revisit the respondent and correct the errors.

All the questionnaires were checked additionally by the supervisors to ensure that i) all skip and filter instructions had been followed; ii) all responses were legible; iii) only one response code for an item had been crossed (X) – unless instructions permitted more than one response; and iv) responses to the open-ended items had been recorded satisfactorily.

At various stages, the supervisors placed all completed questionnaires in an envelope, sealed it, and recorded the number of completed questionnaires and consent forms for that district and the date of completion in a record book. The questionnaires were couriered to the Human Sciences Research Council's office in Cape Town on a weekly basis.

4.5.2 Data capture

4.5.2.1 *Quantitative data capture*

The survey data were captured by trained data capturers at the Human Sciences Research Council in Cape Town using SPSS version 15.0. The accuracy and completeness of the questionnaires, especially where open-ended items were concerned, were checked again for corresponding responses to the items and that skip patterns had been followed correctly. Frequency distributions were run to check that all variables contained values in the accepted range and variable labels or definitions. Outlying values were followed up and corrected.

4.5.2.2 *Qualitative data capture*

The data collected in the two qualitative studies were captured as follows: On completion of an interview with a respondent in the follow-up, in-depth interviewing study, the researcher wrote up raw field notes and later transcribed them into a word processor. The raw (verbatim) data were similarly captured in a word processor, and translated from Xhosa to English by the researcher; transcripts of the translations were later verified by an independent translator (a person with tertiary education degree). Summary notes of the captured data were made in preparation for content analysis and interpretation.

At the end of an interview with a key informant, the researcher wrote a summary, in which themes and issues in the information provided by the key informants were recorded. Insights developed by the researcher during an interview were linked to the information. Audio-recorded data were transcribed by the researcher and categorised in domains**.** Where interviews were not audio-recorded, the researcher wrote up the manually recorded information and managed it similarly.

4.6 DATA ANALYSIS

Data analysis was undertaken in three parts: 1) The survey data; 2) the qualitative case study data; and 3) and the key informant interview data.

4.6.1 Survey data analysis

Analysis of the quantitative data was descriptive: characteristics of the sample were described (Hardon et al., 1995; Katzenellenbogen, et al., 1991) using the SPSS programme as follows:

4.6.1.1 *Univariate analysis*

Frequency distribution tables, graphs and measures of central tendency such as means, standard deviation and score ranges were compiled. Cross tabulations were made, e.g. between caregiving and receipt of support – such as a government grant, and between caregiving and marital status. Age means were compared using analysis of variance (ANOVA), while cross tabulations and categorical variables were analysed applying the chi squared technique. Fisher Exact test was employed whenever any cell was less than 5. All analyses were carried out using SPSS version 17.0. A probability value of 0.05 or less was taken as significant.

4.6.2 Case study data analysis

The captured data were classified and content analysed. Content analysis was used to determine the presence of certain words or concepts within texts or sets of texts. The text was broken down into manageable categories on a variety of levels – e.g. words, phrases, sentences or themes – and then examined using a basic method of content analysis, e.g. conceptual analysis (Krippendorf, 2004). The purpose of classifying qualitative data for content analysis is to facilitate the search for patterns and themes within a particular or across cases (Patton, 1990). First, comprehensive information is gathered on each case: i.e. interview data, observation data, and researcher impressions about the case. Once accumulated, a case record is written up, which involves pulling together and organising all of the data about the case. After this, the organised information is edited, redundancies are removed, and information that belongs together is combined in categories. The case record is then arranged topically for easy access. Thus, case records represent data organised at a level beyond raw case data.

Analytical categories in which the data were organised in the unstructured interviewing study were: i) A socio-demographic profile of the caregivers; ii) a description of their health status; iii) their level of knowledge of HIV and AIDS; iv) formal and informal support available to them; v) the household members' knowledge of the status of the PLWHA and related stigma; and vi) the carers' concerns about co-resident grandchildren and him/herself.

Additional analysis entailed comparing and contrasting cases. Nonetheless, each case was understood as a representation of a particular phenomenon of interest to the study.

4.6.3 Key informant interview data analysis

The data from the key informant interviews was content analysed in a similar way to the data for the case studies. The key informant interview data was organised in six domains: 1) Knowledge of and availability of policies and programmes to support older caregivers; 2) the role of the provincial government department or NPO in providing support to caregivers; 3) older persons,' or their representative bodies' participation in policy formulation processes; 4) their participation in the monitoring and evaluation of implementation of policy recommendations; 5) the availability of resources to facilitate older caregivers' participation in the development and implementation of HIV and AIDS policies and/or strategic plans; and 6) the informants' opinions on how national policy makers can enable district managers to coordinate activities at a local level in order to support older person households affected by HIV and AIDS.

4.7 TRIANGULATION OF THE DATA

When data have been collected from multiple sources, using a combination of research approaches and techniques – hence, a mixed-methods approach, the data (and results of analyses of the data) need to be triangulated (Green, Caracelli, & Graham, 1989; Silverman, 1993; Morgan, 1998; Creswell, 2003). Triangulation will achieve an integrated and comprehensive analytical outcome and understanding. Thus, triangulation represents synergy in the use of quantitative and qualitative methods, which, when used together, yield "more than the sum of the two approaches used independently" (White, 2002: 513).

In the present study the data from the quantitative and qualitative studies would be gathered sequentially: collection and analysis of the quantitative (survey) data would be followed by the collection and analysis of the qualitative (unstructured interview) data. Although an initial focus would be on the quantitative data, the data of the two qualitative studies would then need to be integrated with the survey data. Thus, results of the analysis of the qualitative data (the analyses of the data from the multiple sources shown in Chapter 5) would be used in an interpretation of the findings of an analysis of the quantitative data. When triangulated, should unexpected results arise in the analysis of the quantitative data – as suggested by Morse (1991), the results of the analyses of qualitative data could be used to examine the surprising, or unexpected results in more detail.

At the same time, understanding the support needs of caregivers at a household level through an analysis of the qualitative data will be useful, if policy recommendations are to be made to address those needs. Such an understanding would not be achieved from an analysis of data collected using a structured survey questionnaire alone. The results of the analyses of the data from the multiple sources, in terms of the use of a mix-methods design, should thus be triangulated, towards the end of the analyses of the data in Chapter 5. Statistical techniques will not be employed in the triangulation of the data; rather, the three sets of data will be integrated (triangulated) qualitatively and comparatively, largely to identify areas of convergence and/or divergence (Creswell, 1994).

4.8 LIMITATIONS OF THE STUDY METHODOLOGY

All research methodology and research designs have limitations, and the present study has its own biases and limitations. How bias may have entered the study and the data, and how the bias was managed, as well as other limitations of the study are discussed below.

- All households visited appeared on a list of clients of NPOs included in a database compiled by the relevant provincial departments of Health and Social Development. The survey sample was thus biased towards households with a co-resident older carer that had access to some form of intermediate support from an NPO, through the government's subsidisation of the NPO, and appeared on that list of NPOs. The results cannot thus represent the general population of households with PLWHA, that may not benefit through assistance from NPOs or other support agencies, that receive government subsidisation. Moreover, a large number of affected households in which an older carer is resident, which do not access support from a subsidised NPO, may not be represented in the dataset;
- The survey sample was drawn in only three of South Africa's nine provinces. Affected households' situations and caregiving practices and challenges in the other six provinces may differ. The study findings will thus not be generalisable to affected households in the other provinces, or to South Africa as a whole;
- The study findings may neither be generalisable to households that differ demographically from those in the departments' database: e.g. households without co-resident grandchildren and households in the other six provinces.

- Carrying out case studies in only a single province is similarly a limitation of the qualitative component of the study data.
- The inclusion of only three NPO key informants also limits generalisation of the key informant data.
- Bias may appear in the case study data through the purposive selection of the respondents for these studies, as well as the selection of the key informants;
- The problem of stigma associated with HIV and AIDS prevented the identification and random selection of households, through sensitivities in approaching the households, or indeed the households' access of help from an NPO. Thus not all affected households with an older carer had an equal probability of being recruited into the sample;
- Some bias may have occurred due to the non-response, or refusal of some respondents to be interviewed, whose responses may have differed (e.g. socio-economically) from those who agreed to participate in the study, as well as in the non-solicitation of information on household income and expenditure.
- Although careful measures were taken to reduce bias, bias may nevertheless entered the qualitative data during the translation of the transcripts from the language in which an interview was conducted into English;
- The non-inclusion of a control group of older persons who do not care for PLWHA in their household may limit generalisation of the findings to the population of older caregivers;
- The non-application of standardised instruments to measure caregiver stress, depression, anxiety and burden of care, because of a lack of such an instrument validated in an African setting, may be an omission, but was occasioned by a methodological dilemma and decision.

Limitations of the study methodology as a result of factors extraneous to the study's objectives are as follows: 1) The study did not discern between older carers who care for a PLWHA on anti-retroviral treatment and a PLWHA not on treatment, or a PLWHA who is using alternative treatments such as herbs from a traditional healer, or a combination of therapies. 2) The dissertation makes only a limited contribution to an understanding of the extent that cultural norms played a role in the empirical study's overwhelmingly female caregiver profile. 3) The study was unable to differentiate the extent, or impact of the caregiving burden on older carers who are beneficiaries of an old age grant and those who do not receive a grant – in the latter case possibly owing to age ineligibility.

4.9 ETHICAL CONSIDERATIONS

Ethical considerations of the study and how they were dealt with are outlined below:

- Ethical approval to conduct the study was obtained from the Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (Application Number REC 335/2005) (Annexure 7);
- An information/consent form (written in the language of the respondent) explaining the purpose of the study and how the data would be managed was handed to each respondent who indicated a willingness to participate in the study. A respondent was assured that he/she could withdraw from the study at any time and without any penalty to him-/herself. On recruitment, a respondent was required to sign an informed consent form (Annexure 1), written in his/her own language, which was explained fully to the respondent by the fieldworker. Signature of the form indicated his/her understanding of what would be required of him/her, and that he/she was not coerced but willing to participate in the study;
- Neither a respondent's name nor address appeared on the cover sheet of a questionnaire submitted for data capture. The anonymity of all respondents in the reporting of the study results was thus ensured, and was adhered to during data capture and analysis of the data;
- No invasive procedures or tests were carried out on the respondents;
- A pamphlet with local useful resource information (e.g. offices that provided information and advice on HIV and AIDS, financial assistance, social work services, volunteering services and office counselling) (Annexure 3) was handed to each participating household at the end of the interview;
- Information provided by the survey respondents, the sub-sample for the case studies and the key informants was kept confidential by the researcher. No key informants are identified in the capture and analysis of the data. The completed questionnaires and interview schedules, and the audio-recordings will be destroyed once this thesis has been accepted;
- No remuneration or incentive, in cash or kind, was given to the respondents, to avoid a risk of bias in the recruitment of the sample and the data, and to minimise a risk of violation or exploitation of fieldworkers in the field. Participants were informed that the information they provided would assist policy makers and the planners of support

programmes for older caregivers such as themselves (see Annexure 1), but that participation in the study would not offer them any direct material benefit.

CHAPTER FIVE: ANALYSES OF THE DATA

5.1 INTRODUCTION

Data collected in the survey in the three provinces were captured and analysed using the SPSS programme. Data collected in the follow-up, in-depth interviews with ten of the original survey respondents were content analysed and written up as case studies (the case studies are shown in Annexure 1). Data collected in the semi-structured interviews with nine key informants – six government representatives and three managers of NPOs that serve older persons – were similarly managed and content analysed. In the case of both qualitative studies – that is, the latter two studies – the interviews were audio-recorded where the respondents and informants consented to audio-recording. In three cases, key informants did not consent and their responses to open questions were recorded manually by the researcher. Transcripts of audio-recordings and manual records, translated from Xhosa into English, were content analysed by the researcher.

The results of the analyses of the data from the three sources – a quantitative survey and two qualitative studies – are presented in three parts: Part 1: Analysis of the survey data; Part 2: Analysis of the in-depth interview data; and Part 3: Analysis of the data from the key informant interviews. The study data were therefore collected using a mix of quantitative and qualitative research methods. The results of the analyses of the three datasets are triangulated towards the end of the chapter.

PART 1: SURVEY DATA

5.2 ANALYSIS OF THE SURVEY DATA

5.2.1 Realised sample

The realised sample for the survey is shown in Table 5.1 below. During sampling a concerted effort was made to ensure a high recruitment rate. To this end, i) meetings were held with the management of sampled NPOs (who directed interviewers to affected households with older carers) to explain the aims and purpose of the study, and to elicit the NPO's assistance; ii) only interviewers who had matriculated and were involved in a campaign to combat HIV and AIDS at a community level (e.g. as HIV counsellors) were recruited to conduct interviews;

and iii) up to three revisits to a household to recruit a respondent (if the respondent was absent on previous

Table 5.1: Realised survey sample, by province, geographical area and gender (percentage distribution and frequencies)*

Province	Gender				Total	
	Males		Females			
	%	n	%	n	%	N
KwaZulu-Natal						
Urban[1]	8.3	6	91.7	66	-	72
Non-urban[2]	-	-	100.0	30	-	30
Subtotal	22.2	6	34.5	96	33.4	102
Eastern Cape						
Urban[3]	25.8	8	72.4	23	-	31
Non-urban[4]	13.8	9	86.2	56	-	65
Subtotal	62.9	17	28.4	79	31.5	96
Western Cape						
Urban[5]	1.4	1	98.6	68	-	69
Non-urban[6]	7.9	3	92.1	35	-	38
Subtotal	14.8	4	37.1	103	35.1	107
Total	8.8	27	91.1	278	100.0	305

* Percentages in columns in this table and subsequent tables may not have added up to 100 and have been rounded off.

1 Chesterville, Umlazi and Lamontville (Durban).
2 Edendale, Pata, Ntuzuma, Swayimane and Mbalenhle (Pietermaritzburg).
3 Umtata and Newrest.
4 Lusikisiki and Flagstaff.
5 Khayelitsha, Nyanga and Gugulethu (Cape Town).
6 Ashton, Robertson and Maccassar.

visits) were undertaken before the household was substituted with another household in the same geographical area.

Three NPOs, which the researcher approached initially for referrals to households that would meet the study criteria, refused to participate in the study: one in the Western Cape Province and two in the Eastern Cape Province. These NPOs were substituted with NPOs that operated in the same geographical area and did similar work. The main reasons advanced by the three NPOs that refused to participate were a need to protect the identity of their clients, and that

neither the NPO nor clients had ever been given feedback by researchers whom they had helped previously. Numerous NPOs and respondents in the course of the survey in fact complained that they did not benefit directly from research in which they participated. Two NPOs in the Eastern Cape Province, operated by older persons and aimed at supporting orphaned children, did not support older carers of PLWHA as such, and did not therefore meet the criteria for inclusion in the survey sample.

Despite the refusal of three NPOs and six households to participate in the survey, a 100 per cent response rate was achieved through substitution. The sample substitution rate for NPOs was 14.3 per cent and for households, 1.9 per cent. The total sample numbered 305 older carers.

Table 5.1 gives a breakdown of the realised sample by province, geographical area and gender, shown as percentage distributions and frequencies. The largest provincial sub-sample realised was in the Western Cape (WC), followed by the sub-samples in KwaZulu-Natal (KZN) and the Eastern Cape (EC).

5.2.2 Socio-demographic profile of the sample

The socio-demographic profile of the survey sample is shown in Table 5.2, according to province and geographical area, as percentage distributions. More than nine in ten (91.1%) respondents who were primary carers to PLWHA and OVC were female. The majority of the respondents were of South African descent. The mean age of the sample was 65.9 years (SD = 8.3 years). The mean ages by province were Eastern Cape: 65.5 (SD = 7.4) years; Western Cape: 63.5 (SD = 8.7); and KwaZulu-Natal: 68.7 (SD = 7.8) years. The differences were not significant ($F = 1.42$, $p = 0.06$.) The mean age of the male respondents was 63.4 years and of female respondents, 66.1 years.

More than four-fifths of the sample (86.2%) headed their household, i.e. they were the main decision maker in the household. Most spoke one of two major Nguni languages in South Africa, namely isiXhosa and isiZulu. Three-quarters of the sample (75.6 %) was aged 60 years and over. Only slightly more than a third (35.5%) was still married; thus almost two-thirds (64.5%) may have lacked the support of a spouse and been vulnerable. Only three in ten respondents (29.5 %) had had an education level beyond Standard 6 (eight years of

schooling). In general, respondents in urban areas in all three provinces reported a higher education level than their rural counterparts.

Table 5.2: Socio-demographic profile of the survey respondents, by three provinces and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Total	100	100	100	100	100	100	100
N	31	65	72	30	69	38	305
Nationality							
South African	100.0	96.9	93.1	100.0	100.0	100.0	97.7
Other	-	3.1	6.9	-	-	-	2.3
Head of Household							
("yes" responses)	77.4	87.7	86.1	100.0	82.6	86.8	86.2
Home language							
isiXhosa	96.8	98.5	11.1	6.7	98.6	73.7	65.6
IsiZulu	3.2	1.5	88.9	93.3	-	-	30.8
Sotho	-	-	-	-	1.4	-	0.3
Afrikaans	-	-	-	-	-	26.3	3.3
Age group (years)							
50-54	3.2	7.7	2.8	-	10.1	18.9	7.2
55-59	25.8	13.8	8.3	6.7	31.9	13.5	17.1
60-64	29.0	24.6	20.8	23.3	15.2	16.2	21.0
65-69	25.8	24.6	27.8	40.0	21.7	32.4	27.3
70+	16.1	29.2	40.3	30.0	20.3	18.9	27.3
Marital status							
Married	19.4	23.4	44.4	66.7	30.4	36.8	35.5
Widowed	41.9	59.4	20.8	20.0	27.5	42.1	35.2
Separated	9.7	4.7	6.9	-	8.7	13.2	7.2
Never married	25.8	9.4	19.4	13.3	27.5	7.9	17.8
Divorced	-	1.6	5.6	-	5.8	-	2.9
Living together	3.2	1.6	2.8	-	-	-	1.3

Cont/.

Table 5.2 continued:

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Highest level of education							
No schooling	16.1	13.8	13.9	40.0	2.9	15.8	14.4
Sub A and Sub B	6.5	7.7	22.2	13.3	4.3	7.9	10.8
Standards 1 to 3	16.1	26.2	23.6	26.7	14.5	15.8	20.6
Standards 4 to 6	35.5	26.2	25.0	16.7	39.1	31.6	29.5
Standards 7 to 9	19.4	18.5	8.3	3.3	24.6	23.7	16.7
Matriculation	-	4.6	1.4	-	5.8	2.6	3.6
Post matriculation	6.5	3.1	5.6	-	5.8	2.6	4.3

In summary, the predominantly female sample had a low level of education – and by implication, few opportunities for self-advancement and poor access to resources across the life course. The majority of the sample was 60 years or older, and the majority lacked a spouse and therefore spousal support. The majority of the respondents, all of whom were burdened with caregiving, may thus have had heightened vulnerability.

5.2.3 Household information and characteristics

The characteristics of the respondents' households indicate the social and economic situation of the caregivers. Table 5.3 shows that the majority (68.9%) had lived in the same residential area for more than ten years, although more non-urban than urban caregivers had done so. Close to two-thirds of the sample had lived in the same dwelling for more than ten years, with more non-urban than urban respondents having done so, with the exception of respondents in the Western Cape Province.

Table 5.3: Characteristics of the respondents' households, by three provinces and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Duration of respondent's stay in area							
< 1 year	-	1.5	1.4	6.7	-	-	1.3
1- 2 years	6.5	4.6	6.9	3.3	-	-	3.6
3- 5 years	29.0	6.2	12.5	-	2.9	13.2	10.0
6- 10 years	32.3	15.4	26.4	3.3	7.2	15.8	16.1
> 10 years	32.3	72.3	52.8	86.7	89.9	71.1	68.9
Duration of respondent's stay in dwelling							
< 1 year	3.2	1.5	8.3	0.0	1.4	5.3	3.6
1-2 years	6.5	6.2	13.9	6.7	-	-	5.9
3-5 years	32.3	7.7	9.7	10.0	5.8	15.6	11.5
6-10 years	29.0	10.8	22.2	10.0	8.7	15.8	15.4
> 10 years	29.0	73.8	45.8	73.3	84.1	63.2	63.6
Household's sources of water (multiple responses permitted)							
River/water stream/pond	59.4	70.0	-	10.3	-	3.2	21.8
Tap (inside house)	16.7	7.8	38.6	3.6	58.8	52.6	32.9
Tap (in the yard)	54.8	23.4	37.1	40.0	31.1	23.7	33.3
Communal tap	38.9	61.1	68.2	31.2	39.3	43.5	41.2
Household's type of toilet facility							
Flush toilet inside house	12.9	7.7	37.5	-	36.2	44.7	25.6
Flush toilet in yard	6.5	6.2	13.9	-	43.5	21.1	17.7
Public flush toilet	-	3.1	-	-	7.2	-	2.3
Pit latrine	71.0	70.8	48.6	100.0	-	31.6	47.5
Bucket toilet	-	1.5	-	-	13.0	-	3.3
Chemical toilet	9.7	3.1	-	-	-	2.6	1.9
No toilet (uses bush, etc.)	-	7.7	-	-	-	-	1.6

Cont/.

Table 5.3 continued

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	%
Household's sources of energy (multiple responses permitted)							
Timber/wood	80.0	56.2	9.7	40.0	1.6	10.5	28.5
Electricity	71.0	73.4	94.4	73.3	84.1	81.6	81.6
Coal/anthracite	6.7	3.2	-	3.3	1.6	-	2.0
Paraffin	62.5	76.7	23.6	3.3	36.1	26.3	38.3
Gas	6.8	8.1	9.9	3.4	6.8	8.1	8.6
Size of dwelling							
One room	6.5	4.6	9.7	10.0	5.8	2.6	6.5
Two rooms	19.4	18.5	34.7	6.7	14.5	18.4	20.3
Three rooms	54.8	35.4	11.1	23.3	20.3	34.2	26.9
> Three rooms	19.4	41.5	44.4	60.0	59.4	44.7	46.2
Household's sources of income (multiple responses permitted)							
Social old age pension	79.2	20.8	59.4	40.6	43.7	57.0	65.9
Child support grant	20.9	49.2	33.3	26.7	50.7	68.4	43.9
Employer pension	9.7	10.8	8.5	3.3	-	2.6	5.9
Remittance from family	20.0	6.2	13.9	-	-	5.3	7.2
Employment	3.2	6.2	7.0	-	13.0	13.5	7.9
Self-employed	19.4	3.1	13.9	-	13.0	10.5	10.2
Hawking/odd jobs	9.7	6.2	2.8	3.3	15.9	2.6	7.2
Welfare organisation	3.2	3.1	8.3	-	1.4	-	3.2
No income	3.2	1.6	8.5	7.7	4.4	6.1	5.0
Household's perceived financial situation ("yes" responses)							
Not enough money for basic expenses	38.9	61.1	62.0	38.1	64.4	35.6	78.0
Have enough money for food/clothes, not other things	16.7	83.3	86.2	13.8	85.7	14.3	33.6
Have most basic household items	34.7	65.3	75.7	24.3	81.7	18.3	47.9
Have some money for extra things	-	100	-	-	20.0	80.0	2.9

Table 5.3 reflects the extent to which a large number of the households lacked basic amenities. Slightly over two-fifths (41.2 %) obtained water from a communal tap; only a third (33.3 %) had piped water inside the dwelling; and the remainder (21.8 %) were dependent on water from unprotected sources such as a river, stream or pond. Households in the Eastern Cape Province were more dependent on an unsafe water source (urban households 59.4 %, non-urban households 70.0 %) than households in the other provinces. Households with no inside piped water lacked an inside flush toilet – a particular hardship for both older carers and PLWHA. Almost half of the households (47.5 %) used a pit latrine: more than two-thirds of caregivers in urban and non-urban areas of the Eastern Cape and all caregivers in the non-urban area of KwaZulu-Natal did so.

More than three quarters (81.6 %) of the households had electricity and more than a third (38.3 %) used paraffin as the main source of energy. More than two in five caregivers (46.2 %) lived in a dwelling with three or more rooms; fewer than a third (26.9 %) lived in three-roomed dwellings. In non-urban areas, the respondents' dwellings were mainly built from inexpensive materials such as mud bricks and thatched roofs. In urban areas, the dwellings were either built with brick, or in the case of shacks, with timber and galvanized corrugated iron.

As is evident in Table 5.3, most of the caregivers' households in this study were of low socio-economic status. The majority of the caregivers and household members also depended on state social security. Two-thirds (65.9 %) of the respondents received a social old age pension; a quarter (24.3 %) were not yet age eligible to receive one. More than two fifths (43.9 %) of the households received one or more child support grants. Only a small percentage of caregivers (10.2 %) reported that they generated income by selling perishables in their communities to supplement their household's income. Reporting on the household's financial situation according to fixed statements, more than three-quarters of the caregivers (78 %) perceived that their household did not have enough money, and less than half (47.7 %) reported that their household had money for basic items. Across all households, the social old age pension appeared to be the household's main source of income. However, a quarter of the caregivers did not access the grant, because they were not yet age eligible to do so.

5.2.4 Health status of the respondents

Two measures were used to assess the health status of the sample: 1) A self-rated health status scale which indicated the respondents' rating of their health as "excellent, "good," "fair" or "poor." 2). A comparative health status scale which required the respondents to rate their health as "better," "the same" or "worse" than that of their peers**.** Table 5.4 shows that four-fifths of the respondents overall (81.3 %) rated their health as fair to poor, while almost three in ten (28.2 %) and three in five (60 %) in KwaZulu-Natal's non-urban areas rated their health as poor, respectively. When asked to compare their present health status to that of their peers, slightly more than three-quarters (76 %) rated their health as the same or worse than that of their peers.

The respondents reported having a number of chronic conditions that may have compromised their health and functioning. A list of self-reported conditions, and indication of whether a condition was being treated or not, are shown in Table 5.5. Leading chronic health conditions in the sample were hypertension (60 %), arthritis (55.3 %) and stress (42.9 %).

5.2.5. Respondents' knowledge of HIV and AIDS

The percentages of caregivers who reported they were knowledgeable about HIV and AIDS (84.3 %), shown in Table 5.6, was high. Although almost all (97.3 %) knew that AIDS is caused by a virus, more than half of the caregivers in non-urban areas of the Western Cape Province believed that AIDS is punishment from God.

Slightly more than two-thirds of the caregivers had learnt about HIV and AIDS from health professionals (67.6 %), followed by the radio (61.3 %) and television (50.9 %) as main sources of information. More than four in five respondents (83 %) reported that they had understood the information provided. Slightly more than nine-tenths (94 %) knew that HIV can be transmitted through unprotected sex. Four in five (80.3 %) knew that the virus can be contracted through an exchange of body fluids, such as blood. Overall, the caregivers' knowledge of modes of transmission of the virus was therefore high.

Table 5.4: Health profile of the respondents, by province and urban and non-urban area (percentage distribution)

Characteristic	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Self-rated health Status							
Excellent	-	3.1	4.2	-	5.8	5.3	3.6
Good	29.0	15.4	18.1	-	7.2	23.7	15.1
Fair	61.3	70.8	44.4	40.0	46.4	55.3	53.1
Poor	9.7	10.8	33.3	60.0	40.6	15.8	28.2
Self-rated health Status compared to peers							
Better	19.4	32.3	15.3	6.7	36.2	21.1	23.9
Same	64.5	50.8	34.7	26.7	21.7	63.2	40.9
Worse	16.1	16.9	50.0	66.7	42.0	15.8	35.1

5.2.6. Informal help received by carers with daily caregiving to PLWHA

Types of informal help that the caregivers reported they received from various persons or agencies are shown in Table 5.7. When the carers were asked whether they receive any informal support with daily caregiving, less than two-thirds (59.3 %), on average, replied that they do receive support.

Table 5.5: Self-reported health conditions of the sample, and whether the conditions are treated of untreated, by sub-sample and geographical area (percentage distribution)

Condition	Geographical area sub-samples				Total
	Urban		Non-urban		
	Yes, treated %	Yes, untreated %	Yes, treated %	Yes, untreated %	
Health-condition (multiple responses permitted) [1]					
Hypertension (n= 305)	51.7	7.0	51.9	9.8	60.0
Arthritis (n =305)	44.4	14.6	35.3	15.0	55.3
Stress (n = 303)	15.3	37.1	9.0	21.8	42.9
Vision problem (n =301)	19.0	8.5	14.3	18.5	37.5
Loss of memory (n= 303)	10.0	34.7	6.0	18.8	36.0
Diabetes (n=297)	27.1	6.6	19.8	5.3	30.0
Depression (n=299)	13.6	16.6	3.8	5.4	21.0
Hearing problem(n=303)	5.9	11.8	1.5	12.8	16.2
Asthma (n=304)	8.1	2.9	9.1	0.0	10.2
Kidney condition(n=297)	3.6	4.8	6.1	5.3	9.7
Heart condition (n=305)	6.5	2.4	5.3	4.5	9.2
Shortness of breath(n=299)	5.4	6.0	2.3	3.0	8.7
Stomach ulcer (n=304)	4.7	5.3	3.8	1.5	7.8
Tuberculosis (n=304)	1.6	1.3	3.6	-	6.5
Stroke (n=305)	1.8	1.8	0.8	-	2.3
Epilepsy (n=305)	1.2	1.8	0.8	0.8	2.2
Cancer (n=305)	1.2	0.6	1.5	-	1.6

Missing values ranged from one to 12 and were for the following variables: marital status; main source of income; health status; caring for OVC; and organisational affiliation. The missing data may be accounted for by refusal to answer sensitive questions such as marital status, a respondent being uncertain of how to respond. Of the 64 variables measured, data for six variables were missing owing to the foregoing reasons.

Table 5.6: Respondents' knowledge and beliefs about HIV and AIDS, and sources of knowledge, by province and geographical area (percentages of "yes" responses)

Knowledge/belief	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Perceived knowledgeable about AIDS not bold	100.0	90.8	91.7	73.3	68.1	84.2	84.3
Knows AIDS is caused by a virus not bold	100.0	98.3	98.5	91.3	97.8	93.8	97.3
Beliefs							
Believes AIDS is caused by witchcraft	-	-	-	-	6.4	3.1	2.0
Believes AIDS is caused by poor nutrition	13.3	10.2	8.8	-	13.0	12.5	10.1
Believes AIDS is a punishment from God	6.7	39.0	2.9	-	42.2	58.1	25.0
Sources of knowledge (multiple responses)							
Television	56.7	48.3	72.7	22.7	9.3	81.2	50.9
Radio	96.7	70.0	76.5	26.1	7.0	78.1	61.3
Newspaper	27.6	26.7	64.7	19.0	9.3	43.8	35.6
Pamphlets/magazines	41.4	51.7	65.7	19.0	7.0	68.8	46.0
Doctor/nurse	93.3	66.7	52.4	80.0	60.9	77.4	67.6
Understands information from the source	70.0	88.3	79.4	69.6	97.9	84.4	83.0
Perceived modes of HIV transmission (multiple responses permitted)							
Kissing	6.7	-	3.0	4.3	2.1	-	2.3
Using the same toilet seat as a PLWHA	6.7	-	1.5	-	-	6.7	1.9
Touching a PLWHA	3.3	3.3	9.2	-	2.1	3.1	4.3
Drinking from the same mug as a PLWHA	-	-	-	-	-	-	-
Breathing the same air as a PLWHA	-	6.8	1.5	-	2.3	12.5	3.9
Exchanging body fluids with those of a PLWHA	40.0	81.7	93.9	60.9	83.0	96.9	80.3
Having unprotected sex	96.7	91.7	95.3	87.7	97.7	93.8	94.0

Table 5.7: Types of informal help received by caregivers to PLWHA, by province and geographical area (percentages of "yes" responses)

Help source/ Type of help	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Receives help with daily caregiving							
Yes	80.6	75.4	68.1	23.3	42.0	57.9	59.3
Helper/help agency (multiple response permitted)							
Husband/partner	-	6.1	18.8	-	20.8	8.3	10.7
Child(ren)	16.0	36.0	36.0	28.6	37.0	8.3	36.1
Grandchild(ren)	4.0	10.0	20.4	-	12.0	8.3	11.7
NGO/CBOs (counsellors; home carers etc)	88.5	82.0	52.0	28.6	28.0	70.8	63.7
Community (nurse)	73.1	18.0	18.0	-	28.0	8.3	25.3
Nurse aid	32.0	2.0	16.0	-	-	-	9.4
Neighbours	8.0	51.0	24.5	-	12.0	16.7	25.7
Other relatives	8.0	42.0	22.4	42.9	34.6	25.0	28.7
Friends	52.0	38.0	14.3	14.3	4.0	17.4	25.1
Type of help received (multiple responses permitted) (n = 305)							
Financial	44.0	24.0	31.9	-	26.1	19.0	27.7
Washing the PLWHA	96.2	76.0	50.0	28.6	70.4	50.0	65.8
Feeding the PLWHA	100.0	82.0	54.9	84.6	62.5	71.6	75.9
Administering medication to the PLWHA	100.0	86.0	69.2	28.6	73.1	79.2	78.3
Transporting the PLWHA	68.0	57.1	62.5	57.1	50.0	41.7	56.9
Emotional/spiritual support	92.0	84.0	51.0	14.3	68.4	54.5	67.4

Cont/

Table 5.7 (continued):

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Perceived types of informal help needed by caregiver							
Training in caregiving	96.2	94.1	97.2	96.2	80.0	100.0	94.4
Information on HIV/AIDS	95.8	85.4	80.0	80.0	95.8	91.7	85.9
Guidance on how to care better for PLWHA	100.0	97.9	94.3	73.3	92.0	95.8	92.8
Guidance on how to access government assistance	92.0	72.9	91.4	93.3	79.2	52.2	82.3

Of these caregivers, almost two-thirds (63.7 %) indicated that they received such support from local NPOs. This pattern is common across all three provinces, but more so in non-urban settings. The majority were receiving help with daily activities such as administering medication (78.3 %), washing the PLWHA (65.8 %), emotional and spiritual support (67.4 %), and transporting the PLWHA to places such as health service points (56.9 %). Less than a third (27.7 %) was receiving financial assistance. The type of informal help that high percentages of caregivers reported they needed most was training in caring for a PLWHA (94.4 %), more information on HIV and AIDS (85.9 %), guidance on how to care better for the PLWHA (92.8 %) and guidance on how to access government assistance such as the child support grant (82.3 %). Overall, the caregivers thus expressed a need to be equipped with skills for daily caregiving to the PLWHA and for soliciting financial support from the government.

5.2.7 Formal care services for PLWHA

Table 5.8 gives a breakdown of the frequency of the caregivers' contact with health care service agencies and the perceived level of helpfulness of the health care providers. In the past 12 months, almost two-fifths (39.5 %) had taken a PLWHA to a health service facility

Table 5.8: Pattern of respondents' health care seeking behaviour for PLWHA in the past 12 months, and perceived helpfulness of service providers at the facility, by province and geographical area (percentage distribution)

Pattern of health seeking behaviour	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-Urban	
	%	%	%	%	%	%	%
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Frequency of visit to a health service							
2-3 times a Month	23.1	29.4	40.8	59.3	48.0	43.5	39.5
Once a month	61.5	45.1	50.7	40.7	28.0	47.8	45.6
< once a month	3.8	3.9	7.0	-	4.0	-	4.0
Other	11.5	21.6	1.4	-	20.0	8.7	9.9
Perceived helpfulness of health service providers							
Very helpful/helpful	100.0	98.0	84.3	85.2	93.3	91.7	91.2
Unhelpful/very unhelpful	-	2.0	15.7	14.8	6.7	8.3	8.8

more than twice a month, while slightly over two-fifths (45.6 %) had visited a facility once a month. Nine-tenths (91.2 %) who were visiting a health service point reported satisfaction with the help they received. This finding is at odds with findings of other studies conducted among clients of primary health service points in South Africa (Wouter et al.,2001; Westaway et al., 2003; Myburgh et al., 2005), which have shown consistently low levels of satisfaction with visits to a health care facility.

5.2.8. Disclosure of the PLWHA's status within the family and community

Table 5.9 shows the extent to which members of a caregiver's family were knowledgeable about the status of the PLWHA in the household. More than three-quarters of the caregivers (75.8 %) reported that some members of their family knew about the status. In almost two

Table 5.9: Numbers of members of the respondents' family and community knowledgeable about the PLWHA's status, by province and geographical area (percentages of "yes" responses)

Family members' Knowledge	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Family members* knowledgeable about PLWHA's status	96.2	92.2	69.0	33.3	80.0	87.0	75.8
Knowledgeable family member* (multiple responses permitted)							
Caregiver's spouse/partner	13.0	7.1	25.0	18.2	56.5	25.5	22.8
Child(ren)	50.0	70.2	62.3	63.6	77.3	50.0	63.3
Grandchild(ren)	4.5	31.9	31.5	18.2	60.0	15.1	28.7
Sibling	56.5	42.6	32.1	27.3	52.4	50.0	42.3
Caregiver's parent	-	8.5	14.0	-	35.0	21.1	13.0
Behaviour of knowledgeable family members towards PLWHA* (multiple responses permitted)							
Does not treat PLWHA differently	52.0	40.4	65.5	75.0	25.0	65.0	52.7
Is understanding and supportive	96.0	89.4	91.1	80.0	83.3	95.0	90.1
Avoids physical contact with PLWHA	8.0	-	3.5	-	16.7	15.2	6.0
Blames PLWHA for contracting HIV	6.2	4.9	-	-	-	23.5	3.8

Cont/.

Table 5.9 (continued):

Community Knowledge	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Extent that community members are knowledgeable about the PLWHA's status*							
One person	24.0	16.0	19.7	3.4	8.3	17.4	15.7
A few people	80.8	60.3	43.7	3.4	51.1	43.5	47.5
Widely known	44.0	33.3	50.0	13.3	34.8	43.5	38.2
None	-	6.0	13.6	17.2	9.1	8.7	9.7

* Table 5.9 indicates that the responses were provided by knowledgeable persons in the older carer's household

thirds of these cases (63.3 %), only the caregiver's children knew, but slightly more than two-fifths (42.3 %) reported that siblings were knowledgeable about the PLWHA's status.

No major differences in the extent of disclosure and knowledge of the PLWHA's status are evident across the provinces: neither between urban areas nor non-urban areas. However, it appeared that household members who were knowledgeable about the status were more protective of the PLWHA than members who were not aware of it. More than half the respondents reported that household members did not treat the PLWHA differently: nine-tenths (90.1%) were reportedly understanding and supportive.

However, disclosure of the PLWHA's status in the community was not as common: only slightly more than two-fifths of these caregivers (n = 227) indicated that "a few persons" in the community knew about the status; slightly over a third of 215 caregivers indicated that "everyone" in the community knew about it. The disclosure of a PLWHA's HIV status to the broader community therefore appears to be problematic for older caregivers, given the stigmatisation of the disease. Thus, non-disclosure may impede caregivers' access to much

needed support and solidarity from neighbours, such as practical and emotional support, and advice on where to find and how to access available local resources.

5.2.9 PLWHA's behaviour towards the caregiver

Older caregivers not only have to provide physical, material and emotional care to PLWHA, but may need to contend with abuse from the PLWHA. In addition, they may need to discipline co-resident grandchildren. Table 5.10 shows how caregivers perceived the PLWHA for whom they were caring behaved towards them: Of 231 respondents (the remainder did not respond to this item, seemingly in fear of repercussions from the PLWHA or to protect family dysfunction from the public eye), 14.7 per cent indicated that the PLWHA abused them verbally. Abuse of caregivers was more common in the non-urban areas of the Eastern Cape (29.4 %) and urban areas of the Western Cape (20 %) provinces, than in other settings.

Table 5.10: Caregivers' reported behaviour of PLWHA towards them, by geographical area (percentages of "yes" responses)

Type of behaviour	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Types of behaviour towards caregiver (multiple responses permitted)							
Shouts or becomes angry	12.0	29.4	8.5	10.0	20.0	4.2	14.7
Hits and throws things at caregiver	-	5.9	1.4	3.4	6.7	-	3.0
Accuses him/her of being responsible for illness	-	15.7	1.4	-	-	4.2	4.3
Refuses to talk to him/her	-	3.9	2.9	3.4	-	8.3	3.0
Refuses to take food from him/her	-	7.8	4.3	6.9	6.7	12.3	6.1

5.2.10 AIDS related deaths in the caregivers' households

Table 5.11 shows that an AIDS related death had occurred in slightly more than half of the sample households (55.1 %) in the past two years. More than two-thirds of the households in urban areas of the Eastern Cape (67.7 %) and KwaZulu-Natal (68.1 %) provinces had lost a household member to AIDS. Of the respondents who reported AIDS related deaths in their household in the past two years (n = 168), in almost two-thirds of cases (64.5 %) the deceased was the caregiver's child(ren). In two-thirds of cases (66 %), the deceased had lived his/her entire life in the house where he/she died. In three-quarters of cases, the deceased had contributed financially to the household. About a quarter of the carers (24.4%) had cared for the deceased for between four and seven months before s/he died. Of the caregivers who indicated where the PLWHA had lived and contracted the disease (n = 180), more than a half of the PLWHA (57.5 %) had lived in another city – and may have returned to the parent's home when they became ill. The majority of the caregivers (53.4 %) had first heard about the PLWHA's status from a health service provider, such as a doctor, nurse or other health provider in a clinic or hospital.

Table 5.11: Deaths in surveyed households due to AIDS in the past two years and the trajectory of the death/s, by province and geographical area (percentages of "yes" responses)

AIDS related death	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
AIDS related death in the household in last two years	67.7	53.8	68.1	53.3	52.2	28.9	55.1
Relation of the deceased to the caregiver							
Child(ren)	52.2	83.3	64.7	50.0	69.7	36.4	64.5
Spouse/partner	8.7	-	5.9	6.7	-	-	3.7
Grandchild(ren)	30.4	13.9	36.0	57.1	22.2	9.1	27.9
Other	-	-	-	3.9	-	-	3.9

Table 5.11 continued

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Deceased had lived with the caregiver all of his/her life	24.0	52.8	73.6	94.4	83.3	58.3	65.5
Deceased had contributed to the household financially	72.0	83.3	78.8	72.2	69.4	75.0	75.9
Number of months the caregiver had cared for the deceased							
Less than one month	4.3	-	5.9	5.6	17.1	36.4	13.8
1- 4 months	17.4	11.1	15.7	16.7	25.7	9.1	16.0
5-7 months	56.5	25.0	27.5	5.6	14.3	18.2	24.5
8-10 months	8.7	16.7	13.7	16.7	8.6	27.3	15.3
10+ months	13.0	13.0	25.5	16.7	34.3	9.1	18.2
Unsure	-	13.9	11.7	11.1	-	-	12.2
Place of residence when deceased was diagnosed with the virus/disease							
In another country	29.4	-	7.1	-	14.3	-	10.9
In a city	47.1	57.9	50.0	33.3	57.1	100.0	57.5
In a rural area	17.6	42.1	42.9	66.7	28.6	-	33.8
	-	-	-	-	-	-	-
Source from whom the caregiver learnt of the PLWHA's status ("yes" Responses)							
PLWHA	13.0	40.0	46.2	41.2	41.9	75.0	41.2
Nurses/doctor/clinic/ Hospital	82.6	48.6	53.8	38.9	50.0	41.7	53.4
Community health worker	47.8	22.9	13.7	17.6	10.3	16.7	20.4
PLWHA's partner	-	2.9	12.2	6.7	-	-	5.0

5.2.11 The situation of affected grandchildren in the households

Table 5.12 indicates the situation of co-resident grandchildren affected by AIDS and difficulties experienced by older caregivers in caring for these children. A total of 222 (72.8 %) caregivers were caring for a total of 616 grandchildren in their household – a mean of 2.7 children per household. Thirty-seven age eligible grandchildren were not attending school. In almost half of these cases, the caregivers indicated that the children were not in school because of a lack of money.

Two-fifths of the caregivers reported that their grandchildren were too young to attend school – and therefore needed full-time care. Of the 222 caregivers who had co-resident grandchildren, slightly more than three-quarters (76.7 %) reported that they themselves pay for the children's schooling; in KwaZulu-Natal, all caregivers were doing so. In the Eastern Cape urban area, more than half of the caregivers (59.3 %) reported that they and other family members pay for the schooling jointly. Caregivers gave various reasons why they were caring for the grandchildren, which ranged from there being no one else to care for them, or the children being "my blood" and the caregivers not being able to do otherwise.

Table 5.12: Grandchildren who co-resided with caregivers and school attendance of the grandchildren, by province and geographical area (frequencies and percentages)

Co-resident grandchildren	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non- urban	Urban	Non-urban	
	n	n	n	n	n	n	
Number of grandchildren in caregivers' households							
1	8	16	15	7	20	5	71
2 – 3	11	25	22	12	19	9	98
4 – 5	4	15	6	11	2	0	38
>5	1	6	2	6	-	-	15
Total	24	62	45	36	41	14	222

Cont/

Table 5.12 (continued):

	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	n	n	n	n	n	n	
Number of age eligible grandchildren not at school							
1	5	3	6	8	1	4	27
2 – 3	-	-	5	-	-	-	5
4 – 5	-	-	5	-	-	-	5
> 5	-	-	-	-	-	-	-
Total	5	3	16	8	1	4	37
Reasons for age eligible grandchildren not attending school (multiple responses permitted)	%	%	%	%	%	%	%
Lack of money	52.4	10.5	71.4	85.7	33.3	18.2	46.7
Child(ren) refuses to go to school	10.0	5.3	7.4	-	16.7	9.1	7.8
Too young	85.7	42.1	25.9	14.3	16.7	9.1	39.6
Has finished school	66.7	21.1	25.9	-	-	-	27.5
Is/are sick/disabled	-	-	7.1	-	-	9.1	3.3
Is/are HIV positive	4.8	-	40.7	-	-	-	13.5
Source of payment for grandchildren's schooling ("yes" Response)							
Caregiver	96.3	80.0	75.4	100.0	69.7	76.3	76.7
Other family members	18.5	6.2	16.4	6.9	11.7	2.6	10.5
Caregiver and other family-members together	59.3	12.5	27.5	7.1	9.8	-	17.8
Child support grant	7.1	24.6	14.5	14.3	8.5	26.3	16.4
An organisation (e.g. an NGO, church)	3.8	4.7	-	7.1	6.7	5.9	5.1
No school expenses	3.7	3.1	26.2	6.9	5.1	-	8.8

5.2.12 Perceived areas of caregiving in which the respondent needs support

Table 5.13 shows the areas in which the caregivers perceived they need support. The area in which they perceived they most needed support was money. More than nine in ten (94.6 %) perceived that they needed "a lot" of financial support. More than half (53.4 %) indicated a need for "a lot" of emotional support. A majority (51.2 %) reported they needed "a lot" of social support.

When asked which essential items relating to caregiving they found most costly, more than three-quarters (78.3%) of the respondents indicated school fees and school uniforms. More than two-thirds (67.1 %) reported that obtaining health care was the most costly expenditure item for them. Of the 297 carers who responded to the item on food provision, almost nine in ten (88.6%) reported that food was the most costly item. More than three-quarters (76.8 %) reported that buying clothes for their grandchildren was most costly. The majority of the caregivers perceived that they most needed help or support with food (90.4 %), followed by access to health care (89.4 %), counselling services (87.1 %) and physical care (65.4 %). Physical, or personal care refers here to bathing, grooming, dressing and feeding grandchild(ren).

Table 5.13: Perceived areas of caregiving in which the respondents need support and how much, and how costly essential items are for them, by province and geographical area (percentage distribution)

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-Urban %	
Total N	100.0 31	100.0 65	100.0 72	100.0 30	100.0 69	100.0 38	100.0 305
Financial support							
A lot of support	100.0	93.7	97.2	96.7	95.5	84.2	94.6
Some support	-	1.6	1.4	-	3.0	5.3	2.0
Don't need Support	-	4.7	1.4	3.3	1.5	10.5	3.4
Physical support							
A lot of support	62.1	51.6	55.7	56.7	30.3	18.4	45.8
Some support	31.0	28.1	41.4	36.7	45.5	47.4	38.4

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Don't need Support	6.9	20.3	2.9	6.6	24.2	34.2	15.8
Emotional support							
A lot of support	60.0	35.5	83.1	63.3	50.0	17.1	53.4
Some support	36.7	46.8	16.9	33.3	34.8	48.6	34.7
Don't need Support	3.3	17.7	-	3.3	15.2	34.3	11.9
Social support							
A lot of support	60.7	47.6	53.5	53.3	52.3	39.5	51.2
Some support	32.1	30.2	38.0	36.7	33.8	39.5	35.0
Don't need Support	7.1	22.2	8.5	10.0	13.8	21.0	13.8
Perceived most costly essential items, by extent							
School fees and uniforms							
Most costly	86.2	82.0	60.9	89.7	89.6	67.6	78.3
Costly	10.3	13.1	33.3	10.3	4.5	18.9	15.0
Least costly	3.4	4.9	5.8	-	6.0	13.5	6.7
Health care							
Most costly	78.6	72.6	83.1	73.3	68.7	5.9	67.1
Costly	17.9	19.4	16.9	26.7	26.9	32.2	23.0
Least costly	3.6	8.1	-	-	4.5	61.8	9.9
Food							
Most costly	96.7	96.8	83.1	80.0	97.0	70.3	88.6
Costly	3.3	3.2	16.9	20.0	-	16.2	9.1
Least costly	-	-	-	-	3.0	13.5	2.3
Clothes							
Most costly	76.7	87.1	56.5	80.0	95.5	61.1	76.8
Costly	23.3	12.9	31.9	20.0	-	25.0	17.7
Least costly	-	-	11.6	-	4.5	13.9	5.5
Transport							
Most costly	28.6	51.7	62.3	73.9	41.4	21.6	47.6
Costly	71.4	33.3	37.7	21.7	27.6	29.7	35.6
Least costly	-	15.0	-	4.3	31.0	48.6	16.7

Cont/

Table 5.13 (continued):

Type of support Needed	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban %	Non-urban %	Urban %	Non-urban %	Urban %	Non-urban %	
Perceived major areas of need for help in caring for grandchildren ('yes' responses)							
Access to medical treatment	100.0	81.2	81.8	100.0	100.0	100.0	89.4
Counselling services	93.8	81.2	90.9	100.0	76.9	50.0	87.1
Food support	100.0	81.2	90.9	100.0	92.3	50.0	90.5
Physical care	87.5	73.3	51.5	50.0	81.8	-	65.4

5.2.13 Support received from the government with caregiving

Table 5.14 shows the respondents' perceptions of how sufficient the government support is that they receive. More than four in five (85.6 %) felt there is a need for government to provide more support to caregivers. Of these respondents (n = 247), more than nine-tenths felt that the government should provide money and a similar percentage felt that it should provide food parcels. Slightly more than four-fifths (82.6 %) wanted the government to support them by improving the condition of their dwelling: for example, by adding rooms such as a bathroom, and/or installing inside taps, a toilet and electricity, which would lighten the burden of caregiving on them.

5.2.14 Religious and social affiliations

Religion and contact with a place of worship played an important role in the lives of the older caregivers interviewed, and provided them with spiritual and emotional support. Table 5.15 shows that nine-tenths of the caregivers (91.1 %) belonged to a religious/faith body. More than half (55.9 %) visited a place(s) of worship every Sunday or more often. Slightly more than two-fifths (41.6 %) belonged to a community support group such as a senior centre or a luncheon club; more than half of the urban respondents belonged to such an organisation, but lower

Table 5.14: Caregivers' agreement with statements pertaining to the sufficiency of government support, and indication of types of government support needed, by province and geographical area (percentage distribution)

Agreement/ Disagreement	Province and sub-sample						Total
	Eastern Cape		KwaZulu-Natal		Western Cape		
	Urban	Non-urban	Urban	Non-urban	Urban	Non-urban	
	%	%	%	%	%	%	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
N	31	65	72	30	69	38	305
Support is sufficient							
Agree	-	-	4.8	-	41.7	20.0	9.2
Disagree	100.0	100.0	90.4	100.0	50.0	80.0	88.2
Not sure	-	-	4.8	-	8.3	-	2.5
Support meets basic needs only							
Agree	100.0	70.0	15.0	20.0	100.0	45.0	47.5
Disagree	-	23.3	62.5	20.0	-	40.0	35.6
Not sure	-	6.7	22.5	60.0	-	15.0	16.9
Government must give more support							
Agree	100.0	86.7	82.9	50.0	100.0	95.0	85.6
Disagree	-	13.3	7.3	-	-	5.0	6.7
Not sure	-	-	9.8	50.0	-	-	7.6
Types of government support needed (multiple responses permitted)							
Food (e.g. food parcels)	100.0	98.3	88.9	73.9	95.0	100.0	93.9
Money (e.g. vouchers)	92.6	94.9	97.7	95.7	93.4	100.0	95.5
Home improvement (e.g. inside toilet, bathroom)	92.6	91.5	75.0	73.9	77.0	84.8	82.6

Table 5.15: Religious and organisational affiliation of the caregivers, by geographical area (percentages "yes" responses)

Affiliation	Geographical area		Total
	Urban	Non-urban	
	%	%	
Total	100.0	100.0	100.0
N	151	127	305
Belongs to a religious/faith body	87.8	95.5	91.1
Frequency of visit to a place of worship (n = 272)			
Every Sunday or more often	42.0	71.3	55.9
Two/three times a month	26.6	19.4	23.2
Once a month	12.6	5.4	12.9
Less than a month	2.1	0.8	1.5
Stopped attending because of caregiving	2.8	0.8	1.8
Belongs to a social Organisation			
Community support group (senior centre) (n = 298)	54.4	24.8	41.6
Burial society (n = 300)	40.6	52.3	45.7
Stokvel (community saving scheme) (n = 291)	13.7	10.0	11.9

numbers in non-urban areas as fewer such facilities are available in these areas. Slightly more than a tenth of caregivers (11.9 %) belonged to a *stokvel* (a community savings scheme). Close to half (45.7 %) of 300 respondents reported that they belong to a burial society; in the non-urban areas, more than half (52.3 %) belonged to one. Membership of these types of societies may be viewed as a financial coping strategy in this population.

5.2.15 Discussion

The analysis of the survey data has shown that older caregivers experience multiple difficulties during the sickness of a PLWHA as well as after his/her death. Key findings from the analysis of the effects of the disease on affected households and older carers'

responsibilities were as follows: 1) The majority of the caregivers had particular vulnerabilities, as a result of their low socio-economic status, lack of access to help resources, little formal support and the burden of care. 2) The financial situation of the carers and their household was grim; apart from income from a social pension in the majority of cases, and from child support grants in some cases, no other support was forthcoming from the government for carers, such as a caregiving grant. 3) The carers reported poor health generally, aggravated by self-reported chronic health conditions (the conditions were not assessed clinically), hypertension, arthritis and stress in particular. Indeed, the conditions may have been induced or exacerbated by the strain of caregiving and associated responsibilities on the carers. 4) The majority of the respondents were knowledgeable about AIDS, its causation and who is at risk of contracting the disease and how. However, about half the respondents in non-urban areas believed that AIDS is punishment from God. 5) NPOs appear to play a significant role in providing support to older carers and their households, specifically through training on HIV and AIDS, advice on day-to-day caregiving, skills development and financial support. 6) The carers perceived that support from the government to help them with caregiving and related responsibilities was "non-existent." 7) Disclosure of, and stigma relating to HIV and AIDS are problems with which older carers must contend in their community.

A comparison of the data across the three provinces showed the following differences and commonalities: Almost all the caregivers (and by implication the members of the households) were South African (97.7%). All the participants in the non-urban area of KwaZulu-Natal headed their household, compared to 87.7 % and 86.8 % in the Eastern Cape and the Western Cape provinces, respectively – which finding is consistent with the majority of household studies carried out in South Africa (see Makiwane, 2004; Ferreira et al., 2001; Orner, 2006). However, a surprising finding was that two-thirds (66.7%) of the caregivers were married, which is atypical in older women in South African settings, especially in rural areas. An explanation for this anomaly may lie in polygamous marriages, which are common in KwaZulu-Natal, resulting in women in a polygamous relationship heading their household even though married.

STATSSA 2007 survey data indicate that the Eastern Cape Province is socio-economically the most under-developed of the three study provinces, with only 72 % of households having access to piped water, compared to 82 % in KwaZulu-Natal and 98.9 % in the Western Cape.

The Eastern Cape also has the highest percentage of households (19.5 %) without a toilet (a similar percentage was found in the present study), with percentages of 7.3 and 5.5 for KwaZulu-Natal and Western Cape, respectively. Similarly, the study found only 68.8 % of houses in the Eastern Cape had electricity, compared to 73.4 % in KwaZulu-Natal and 94 % in the Western Cape. However, the Eastern Cape had the lowest percentage of households living in informal dwellings (7.1%), followed by 8 % in KwaZulu-Natal and 16.8 % in the Western Cape. Informal settlements are more common in the Western Cape due to a high rate of in-migration to the area to seek employment and education opportunities, and under-provision of housing infrastructure (see e.g. Kok & Collinson, 2006).

The respondents' poor socio-economic status undoubtedly makes caregiving more difficult for them. Their particular vulnerability was evident in several indicators in the analysis: socio-economic and health related indicators, and a lack of support, in particular. This finding corroborates similar findings in other studies in SSA countries (see. e.g. Makiwane et al., 2004; May, 2003; Mba, 2003; WHO, 2002a). The housing circumstances of the majority of the carers were reported to be poor and to hamper caregiving. The majority used a pit latrine, obtained water from a communal tap, and complained about cramped living space. Some in the rural areas of the Eastern Cape get their water from unprotected source such as rivers or pond putting them and their dependents at risk to waterborne disease such as cholera. The majority verbalised a need for support from the government to improve their dwelling, which they perceived would help them to cope with the burden of caregiving. Poor environmental and housing infrastructure, or lack thereof, in these and other areas persists 16 years after the advent of democracy, and despite promises of the government to improve the quality of life of all citizens. Nonetheless, what is salutary is that almost two-thirds of the carers received an old age pension from the government.

The financial situation of the carers' households was equally dire. Besides income from a social pension in two-thirds of cases, the households received little other support from the government, other than a child support grant in some cases. Financial support from other family members living elsewhere was limited and not dependable. Only some carers engaged in income generating activities, such as petty trading, to supplement the household's income; the majority did not, or were unable to do so because of caregiving responsibilities. The households' and carers' dire financial situation prompted the majority of the respondents to call for the government to provide money or food vouchers to persons such as them. Even

though PLWHA with a high level of morbidity are eligible for a disability grant, none of the households was in receipt of such a grant. Disability grants could provide much needed relief and a safety net for such households.

The respondents were asked to indicate which items on a list of essentials were most costly and least costly for them. A reason for asking them to rank their household consumption and expenditure needs in this way was to establish areas of major financial burden for respondents relating to caregiving. The results could inform recommendations on areas in which support intervention is most needed. In interpreting this data, the frequencies for "most costly" items were regarded as most important. The areas of need, in rank order, were food (except in non-urban KwaZulu Natal), clothing, health and transport. In the Western Cape, health and transport were least important owing to residents' relative easy access to these services in that province.

Although the older carers were making a valuable contribution by shouldering the burden of care in their household, assuming such responsibility often came at a great cost to them. Apart from the direct financial costs of caregiving, the burden of care affected the carers' health adversely. Older carers, the majority of whom reported having chronic health conditions, merit special attention at health care facilities: not only to optimise their functioning, but to sustain their care contributions as well (Ferreira et al., 2007). Earlier studies have provided evidence moreover of adverse psycho-somatic disorders in older carers as a result of caregiving (see Burton, 1992; Fuller-Thomson & Minkler, 2000; Kelly, 1993; Minkler & Roe, 1993; Shore & Hayslip, 1994).

The respondents' level of knowledge about AIDS was surprisingly high. Nonetheless, a belief that AIDS is punishment from God was fairly widespread in non-urban settings, and indicates a fatalistic attitude, which may be an area of concern in the national fight against the epidemic. This finding concurs with the results of the WHO (2002a) study among older caregivers in Zimbabwe. Hence, by implication, despite the body of information about the disease that is available, a sizeable proportion of the older population seemingly believes only in divine intervention as a solution to the spread of the disease. For this reason, a strong faith in God among the carers may be a coping strategy, in the absence of formal support, to deal with affliction in their household and the burden of caregiving.

Non-profit organisations are clearly playing a crucial role in supporting older carers on a continuing basis. A high proportion of the carers reported receiving assistance from NPOs. The lead taken by NPOs in supporting affected older carers has been reported by Knodel and colleagues (2006) (Knodel et al., 2006) in southeast Asian countries. The lack of formal government support to older carers in South Africa is reflected in the absence or underdevelopment of appropriate policy and programme responses to meet the needs of older carers.

The respondents were virtually unanimous that support provided by the government is insufficient to alleviate the strain of caregiving. Finding of studies conducted by Knodel and colleagues (2006) in Cambodia and Thailand, other highly affected developing countries, in this regard are similar. In the present survey, the older carers indicated that they needed "a lot" of support in the following areas: Money to buy food and other basic necessities; respite care or physical support with daily activities such as feeding, washing and providing medicine to PLWHA; emotional support; and social support. The government does not provide support in any of these areas. Presumably it relies on NPOs to do so. Moreover, where the government does provide support to individuals and families affected by AIDS, none of it is targeted at older carers, particularly in non-urban areas, which substantiates the carers' perception that they are excluded from support programmes.

Apart from caring for PLWHA, the majority of the respondents were caring simultaneously for grandchildren affected by the PLWHA's illness. Although two-thirds of the carers received a social old age pension, and in several cases a child support grant, or several such grants, they still reported experiencing serious financial difficulties. Without formal support, numerous carers may have no option but to prolong the interruption of economic activities after the death of the PLWHA, as they must continue caring for young orphaned grandchildren. As the HIV and AIDS crisis in South Africa is unlikely to abate soon, a growing number of young children will be orphaned in the coming years and a similar growing number of older persons will be burdened with caring for them. In most cases the carers will have to provide psychological and emotional support in addition to physical and material support to the children. Indeed, the carers in the survey indicated that they themselves need "a lot" of emotional support as well.

Not surprisingly, stigmatisation of the disease was found to be a problem in most of the communities in which the survey was conducted, which negative attitude is counterproductive to affected households and family members, and an obstacle for them in accessing help resources. More positively, family members of PLWHA were reported by the respondents to be supportive of the PLWHA, which suggests that anti-AIDS stigma interventions may be accepted at a family level, which will help to strengthen family resilience against the stigma. The radio emerged as a primary source of information on AIDS, which presents a useful option for addressing HIV and AIDS among older carers.

However, also striking in these findings is that men (husbands), albeit fewer than a tenth of the sample, participated in caregiving as primary care providers. The majority of studies conducted on caregiving to PLWHA and OVC have shown that caregiving is essentially a women's responsibility and that males tend not to participate in caregiving directly (WHO, 2002; Ferreira et al., 2001; Schatz, & Ogunmefun, 2005). However, this view has been challenged by feminist theory advocates (Canfield, 1997). In the literature on HIV and AIDS management at a household level, scant attention has been given to men as primary caregivers – to both PLWHA and OVC. Men have typically been viewed as family and household providers, or as providing a supportive role, but not as a primary carer. Although only a few men were interviewed as primary carers in the present study, older men should nonetheless be regarded as valuable players in caregiving, even though they may lack the caregiving experience that older women have, and may not be expected culturally to provide care. HIV and AIDS intervention programmes thus need to take into account that some older men do render care to PLWHA and OVC, and may indeed do so increasingly, and should include them in interventions.

Another consideration is that caregivers to PLWHA and OVC are likely to suffer health problems associated with the stress of caregiving, which may be especially true for male caregivers (see e.g. Kespichyawattana & Van Landingham, 2003). Moreover, male caregivers tend to seek health care for such ailments later than female caregivers. Hence, it is important that interventions take these considerations into account as well – and help male caregivers to understand possible consequences of caregiving for their health, to know where to access health care, and to know how to take care of their health. Finally, male caregivers should not be overlooked in that they constitute a positive role model for other men in their

communities: in challenging culturally defined stereotypes of male and female specific roles within families, and contributing to the care management of the epidemic.

Other similarities and differences across the provinces were as follows: Slightly more than two-thirds of the caregivers had lived in the area in which they were interviewed for ten years or longer, which suggests that they enjoy a strong social network (see table 5.3). A surprising finding, indicating differences, was that 58 % of non-urban respondents in the Western Cape believed that AIDS is punishment from God, compared to only 3 % of respondents in urban areas of KwaZulu-Natal (see table 5.6). This difference is noteworthy, highlighting possible fatalistic views about the disease held in those areas, and suggests that HIV and AIDS information campaigns should be strengthened and adapted accordingly.

Although the majority of studies on caregivers report poor self-reported health status, the present study's data differ. Only 40.9 % of the respondents rated their health status as similar to that of their peers, while 35.1% reported that their health was worse (than that of peers). Heterogeneity among carers in this regard should thus be recognised.

Findings of analyses of the data suggest that more needs to be done for older carers on a number of levels. The findings are certainly relevant to the development of old age support policies in South Africa, particularly to benefit older caregivers. The findings also underscore a need for intergenerational support in households affected by AIDS in which co-resident older persons are caregivers. Not least is the poor socio-economic status of the majority of these households that needs to be addressed, and the combined effects of caregiving and poverty ameliorated. Interestingly, the results indicate that older caregivers in urban areas are more likely than their counterparts in non-urban areas to lack sufficient money for basic expenses – in part due no doubt to a higher cost of living in urban areas. Moreover, urban dwellers need to earn income to be able to purchase items to meet basic needs, such as staple foods and energy, whereas rural dwellers may to an extent rely on subsistence agriculture, like working their fields and raising stock (sheep, goats, chicken) to feed themselves and their household.

The respondents in the Eastern Cape appeared to have better access to social support than their counterparts in the other two provinces. Social grants and welfare services appear moreover to be targeted effectively at poor households in this province. A STATSSA (2008)

survey indicated that of the three study provinces, the Eastern Cape has the highest percentage of welfare recipients (16.6%), compared to KwaZulu-Natal (12.6%), and the Western Cape (8.2%). However, HIV and AIDS is the leading cause of death in both men and women in the Eastern Cape; in 2000 Bradshaw et al. reported an overall rate of 20%, and AIDS being the leading cause of death in children younger than five years. Nonetheless, since 2005, the provincial government has established substantial infrastructure and services to fight the disease.

A high proportion of PLWHA in non-urban areas of the Eastern Cape (61.3 %) had indeed learned of their status when their caregiver had taken them to one of these accredited health service centres (table 5.8). The majority of these caregivers had also found the health care providers to be helpful. This finding contrasts with the low reportage of the PLWHA status from the other two provinces, and may be attributed to the fact that carers in the Western Cape and KwaZulu-Natal provinces have more options (agencies/facilities) available to access information about the PLWHA's status, such as, private health institutions, general practitioners and voluntary counsellors at VCT clinics. On the other hand the carers themselves in the Eastern Cape Province appeared more reluctant than counterparts in the other two provinces to use health services – possibly due to poor and ageing infrastructure (e.g. roads, buildings and telecommunications). Poor roads make travelling and access to critical services difficult for the majority of older residents, especially in non-urban areas. However, difficulties experienced at service points may also contribute to a reluctance to seek care at the centres. Staff shortages and staff attitudes may be problematic, anecdotal evidence of which has been reported recently (2008/2009) in the media, as well as shortages of medications and perceived unhygienic facilities.

The matter of PLWHA's access to anti-retroviral therapy is important, in that at the time of the study, major challenges were being experienced in the roll-out, or implementation of the ARV programme countrywide – except in the Western Cape Province. PLWHA's access to the treatment was not assessed in the study, as the results would not have provided reliable information in terms of comparative accessibility. Moreover, according to the Department of Health's HIV/AIDS treatment protocol, PLWHA are only given ARV therapy when their CD4 cell counts falls below 200, and CD4 count values were neither measured in the survey.

The findings of the analysis of the survey data offer measurable outcomes to inform the design of policy responses and interventions that support older caregivers, as well as their sick adult children, and orphaned and vulnerable grandchildren holistically. To a large extent, the survey findings confirm findings of other, albeit smaller and geographically confined studies in this subject area, but also extend notably on earlier findings

PART 2: CASE STUDIES DATA

5.3 ANALYSIS OF THE CASE STUDIES DATA

5.3.1 Introduction

Follow-up in-depth interviews were conducted by the researcher with ten randomly selected older carers who were interviewed earlier in the survey. For logistical reasons, the households were all located in the Western Cape Province, in both urban and non-urban settings. Four households were identified in Khayelitsha and two in Nyanga (urban settings), two households in Macassar and two in Robertson (non-urban settings). The data gathered was categorised by the researcher. Six categories or domains were selected to classify the coded data, which provided an analytical framework for the qualitative follow-up study. The six domains, which were similar to domains covered in the survey (see sub-sections 5.2.2 to 5.2.8).

Pseudonyms are used for all carers whose responses are referred to the text below. The pseudonyms are used similarly in the ten case studies shown in Annexure 7.

5.3.2 Analysis of the data

5.3.2.1 *Socio-demographic profile of the sub-sample*

With the exception of one carer, who was 59 years old and not eligible for an old age grant, all the carers interviewed were 60 years and over and received a social old age pension. The mean age of the carers was 68 years. All were grandmothers and, on average, had four co-resident grandchildren. All were primary caregivers to the PLWHA and grandchildren. The social pension was their main source of income. Most were unemployed, owing partly to caregiving responsibilities to the PLWHA and grandchildren, and partly to their own ill-health. The majority was widowed. Eight had received primary education and none had an

educational level beyond standard 10; two had no schooling. A number had not completed school owing to a lack of financial resources and/or early marriage. In eight cases, the PLWHA for whom the carers were caring was their adult child; in two cases it was a grandchild.

5.3.2.2 *The carers' health status*

Virtually all the carers interviewed had one or other chronic ailment which was either being treated or was untreated. Common ailments were stress, depression, insomnia, hypertension, diabetes and arthritis, all which can complicate caregiving and limit a carer's full potential to care.

Some carers felt that their caregiving responsibilities aggravated their health condition(s). Mrs Nino, 72 years old, explained the effects that caring for a son with AIDS had on her health: "My son's illness gives me a lot of worries, on top of which I suffer from high-high [high blood pressure]. I sometimes forget to take my diabetes medication. I am very worried that with my worsening illnesses and old age I might die first and I do not know what will become of my child and grandchildren when I am no longer around." What worries Mrs Nino even more is that she suspects that one of her grandchildren might be infected with the HI virus, as he shows most of the symptoms that his father presented with, such as a persistent cough and physical wasting. This concern places a heavy strain on her health (Case study # 1).

Mrs Kamanga, 59 years old, had similar concerns. Widowed, she had lived in various townships around Cape Town, but mainly in Khayelitsha. She was living in a small four-roomed shack house with four other people when interviewed. She explained that: "My household problems are too much for an older person like me. The problems I face in this house affect my health badly. I think I am suffering from a lot of stress, although the doctors at the clinic have not detected it for now. They are only giving me treatment for hypertension, arthritis and sugar diabetes" (Case study # 4).

Mrs Zizo, 65 years old, described the effects that caregiving was having on her health: "Now I have developed a new thing, I spend sleepless nights thinking about this 'bad thing' [HIV and AIDS] that has happened in my house. I suffer from constant headaches ever since I was told that my daughter has been infected by HIV. My diabetes condition has become worse

although I am taking treatment for it. I believe that my health has moved from bad to worse because of the situation in this house" (Case study # 5).

Sleeplessness is a condition from which several caregivers suffered, although not all mentioned it explicitly. Mrs Rory, 73 years old, believed that caregiving relating to HIV and AIDS affected her sleep badly: "My granddaughter's health situation is putting a lot of stress on me, now I have a funning and unusual thing, I wake up at night … and have to take sleeping tablets to be able to sleep at again. Sometimes I cry for no reason." She prays a lot about her granddaughter's condition and hopes that she will be healed one day, as she believes in miracles, she explained (Case study # 9).

A health-related situation reported in all the case studies was that caregiving is not only a physical burden but triggers illnesses and exacerbates existing ailments. New conditions triggered in this way include sleeplessness, worsening hypertension and headaches. Curiously, the majority of the carers reported positive experiences with health service providers: they found them helpful, as was shown in analyses of the survey data, but which is in contrast with findings in other local studies (e.g. Joubert & Bradshaw, 2000). However, some carers who suffered from diabetes felt it was unrealistic for doctors to prescribe special diets for them, as they could not afford to buy the special foods needed with their meagre pension money. A carer reported that she was afraid to take her grandchild to a clinic to be tested for HIV, even though she suspected the child might be infected with the HI virus, as the nurses would "scream" at her if she brought a child without knowing what was wrong. "Some of the nurses at the clinic can be very harsh." By and large, the majority of the carers carried out the role of primary caregiver to a PLWHA and grandchildren despite their advanced age, poor health and lack of support; as a consequence, some felt that their contributions were limited.

5.3.2.3 *The carers' knowledge of HIV and AIDS*

In general, most of the carers knew what HIV and AIDS were: they explained that HIV is a germ (virus) that results in AIDS. Most reported that AIDS manifests in various medical conditions such as tuberculosis, pneumonia and skin lesions (sores on the body), or a combination of these conditions. They also knew that a PLWHA becomes sick over several months before succumbing to the illness. Most reported that the PLWHA apparently contracted the illness through unprotected sex. The majority had acquired knowledge about

the disease at an NPO to which they belonged and after their child had been diagnosed with the disease. However, prior to joining the NPO most had lacked knowledge of the disease, or had a confused and fatalistic idea of what the disease was. Volunteer workers at their community NPO had taught them what they now know.

Mrs Kamanga, 59 years old and widowed, who resided in Khayelitsha, explained: "…AIDS can be cured like any other sexually transmitted disease. And I know of traditional healers who can cure sexually transmitted infections such as *gcusula* (gonorrheoa)." She continues to believe that AIDS is a form of *gcusula*, despite the new knowledge she has acquired about the disease (Case study # 4). Mrs Noor, 76 years old, commented fatalistically as follows: "[I]… believe strongly that it is a punishment from God to wrongdoers and one can't do anything about it. … the bible says there will come a time where there will be incurable diseases because people have sinned in the eyes of God." Mrs Noor also felt that the local Day Hospital needed to supply carers with enough material such as gloves and plastic aprons, as she had struggled a great deal trying to obtain gloves when she was caring for her daughter, now deceased (Case study # 10).

A common feature in the case studies of both the urban and non-urban based carers, as far as HIV and AIDS are concerned, was that prior to joining an NPO the majority had believed that the disease is only contracted by young people, specifically promiscuous youth, and that older persons are not at risk of infection. Mrs Tibo, 60 years old and residing in Macassar (a non-urban area), whose daughter was diagnosed as HIV positive in 2003, explained: "I did not believe [it] when I was told by a doctor about my daughter's status. I thought that HIV is contracted by persons who sell their bodies [sex workers] for money, and those who 'shoot' [intravenous drug users], and not people in marriage or in steady relationships like my child" (Case study # 7). Similarly, Mrs Bidi, 66 years, resident in Nyanga (an urban area), did not know what was wrong with her daughter before her death, nor did she know about AIDS, who is at risk of contracting the disease and whether older persons can be infected with the virus. She did not know that a carer should wear gloves and other protective equipment when attending to a PLWHA. Such information, she pointed out, is not shared on the radio. Nonetheless, it was her view that wearing protective equipment to wash her own child would be inappropriate and indicate a rejection of her own "flesh and blood," which would be frowned upon culturally (Case study # 8). A reluctance of older carers to wear gloves in these cases was also identified in a WHO (2002a) study in Zimbabwe.

A majority of the carers had learnt about HIV and AIDS from the radio, while some had acquired knowledge from sources such as television, health professionals, and pamphlets and magazines. Indeed, the sources of information on HIV and AIDS that the majority of older persons relied on may have been insufficient to equip the carers to protect themselves and those in their care, such as their grandchildren.

5.3.2.4 *Formal and informal support available to the carers*

Although most of the carers received a social old age pension, only a few received a child support grant for grandchildren in their care. None though received any formal support to help them to care for a sick person afflicted with AIDS. Most described the pension as their main source of income. Some referred to it as *inkam-nkam* and *indodla*, which translated means "that which feeds me". Mrs Tiki-Tiki told that: "I cannot wait for the end of the month so that I can receive my *inkam-inkam* to address my household problems" (Case study # 2). Although the regular monthly pension provided a social safety net for the carers, most had misgivings about the amount of the benefit, and explained, for example, that "…my husband's pension and mine are not enough to support three school-going children, two adults and a sick person who needs special care" (Case study # 2).

Carers specifically mentioned a lack of financial resources and how HIV and AIDS were impoverishing their household. Some were trying to augment their income by selling perishables in their communities, such as fat cakes, sweets, fruit and vegetables. Mrs Zozo had this to say: "…it is because of the little things that I sell to make ends meet, that helped me to put bread on the table and send my grandchild to school. … I am concerned that she might not finish school because of scarce financial resources because of this disease…" (Case study # 3).

Mrs Zozo noted that: "…sometimes I have to borrow money from money lenders [loan sharks], and they charge very high interest rates and sometimes confiscate one's ID [identity document] until one pays back the money in full" (Case study # 3). On the other hand some carers identified attractive features of the pension as being its regularity and dependability: they could rely on the same amount being paid to them on the same day each month, which afforded them a sense of financial security.

The carers were asked how the government might support them with their caregiving responsibilities. The majority indicated a need for money, to help them to buy nutritious foods for the PLWHA, to transport him/her to health service points, and to meet grandchildren's schooling related needs, such as books, uniforms and fees. Some said they would like to have a better house, with more rooms, electricity, and a flush toilet and piped water inside the house, which would help them to provide better care. Few carers mentioned support in the form of information and education on HIV and AIDS, but one suggested that the government should include older persons in HIV and AIDS prevention campaigns, which should not only be for young people.

All indicated that they received informal support from NPOs in their residential area, the most important support provided being education and information on how to care for a PLWHA. Mrs Rory, 73 years old, explained: "I was told by the home based care volunteers about HIV and AIDS. They also told me that older persons can contract the disease if they are sexually active and do not protect themselves by using condoms" (Case study # 9). Some indicated that NPOs supported them by equipping them with income generating skills that enabled them to supplement the income they received from the pension. None indicated that they received help from family members and neighbours. However, some respondents in the survey indicated that they received support with caregiving from family members, especially their adult children.

5.3.2.5 *Disclosure of the status of the PLWHA to the caregiver and stigma*

A reluctance to disclose the status of the PLWHA for whom a carer was caring was common. Some distanced themselves from HIV and AIDS and gave it other labels, such as "this problem" and "this thing." Mrs Nino explained that she had not disclosed the PLWHA's status to neighbours, as people would gossip about her family because of "this thing". A fear of rejection and isolation of her family or household in the community was the reason that most carers had kept quiet about the disease (Case study # 1). Other carers' concerns were that grandchildren might be harassed by other children in the neighbourhood. Some were concerned about being judged to have failed as parents by not teaching their children good morals. Mrs Zizo explained: "…I am worried that people will gossip and judge my parenting skills…" (Case study # 5). Nonetheless, one carer felt there was merit in disclosing the

disease: “I tell those who want to know about my grandchild’s illness and telling people the truth has helped me overcome my fear [of it]” (Case study # 10).

Many carers felt that disclosing the illness to other family members and/or neighbours might result in discrimination against, or isolation of the caregiver’s family. HIV and AIDS related stigma is strong in some communities, especially where HIV and AIDS stigma is gender based. HIV positive women who disclose their status are treated more harshly than HIV positive men. Mrs Tiki-Tiki, who resided in Khayelitsha, told that: “One other thing that made me reluctant to disclose my daughter’s status to other people is that, in this township, people with AIDS are treated very badly, especially women are discriminated against and sometimes they are killed violently by some community members. Some people still believe that women are spreading HIV” (Case study # 2). Seemingly, in most of the communities in which the older carers resided, people did not talk openly about HIV and AIDS, which fostered stigma further.

A sentiment that stigma is a greater problem for HIV positive women than for male counterparts has been identified in other studies in South Africa (e.g. Petros et al., 2006). Stigma and discrimination against female PLWHA are barriers to the women’s accessing free VCT and PMTCT services. Mothers who are HIV positive find it difficult to comply with medical advice to formula feed their infants, through a fear of having their HIV status exposed. Older persons, especially older women, are often targets of AIDS stigma. Mrs Kamanga, 59 years, pointed out that: “… another thing is that people in my area still keep old ideas about illnesses, especially when someone does not get cured, people believe the person has been bewitched and fingers might point at me.” Mrs Kamanga added that her son has already accused her indirectly of being the cause of his illness (Case study # 4). An association between HIV and AIDS, witchcraft and older persons is common in some parts of SSA, including South Africa. Older persons are accused by members of their community of being responsible for inexplicable events or ills that befall a community, such as people manifesting AIDS, and in some cases are forced to flee their homes (see Chapter 2). Old age and HIV and AIDS stigmatisation are thus issues that older carers have to contend with in their household and community.

5.3.2.6 *Co-resident grandchildren and caregivers' concerns*

Most carers viewed caregiving as an obligation to a relative in need: care recipients are family members who need to be cared for on an ongoing basis. In general, the majority viewed their grandchildren as being an integral part of their lives and as such they had a duty to care for them. Some had a positive vision for their grandchildren's future. Mrs Zoe explained: "I want my grandchildren to remain at school until they finish school and live a better life than mine which is full of difficulties…" (Case study # 6).

Failing to fulfil an obligation to keep grandchildren in school would imply a failure on the part of the carer to protect, nurture and provide for the future of her own. Caregiving for grandchildren is demonstrated most prominently in the carers' ability to provide four basic necessities for survival: food, health, clothing and shelter. Mrs Tibo told: "… I need to provide them with food, [meet] school expenses, buying clothes … and providing a home for them" (Case study # 7). Although the caregivers may have been concerned about daily responsibilities that challenge their caregiving, such as discipline of grandchildren, most tended to be future-oriented and displayed proactive approaches in seeking support to help them to care for grandchildren. The majority asked for financial assistance so that they could keep their grandchildren in school and the children would not fall prey to HIV infection from older men who buy them expensive items in exchange for sex. "… child(ren) might come under bad influence, as most girls of her age in the community land up stopping going to school because of pregnancy. Some of the girls simply leave school to associate with older men, who buy them nice clothes, cell phones and make them pregnant or give them sexually transmitted diseases" (Case study # 7).

Two carers felt that the government should involve older persons in programmes aimed at combating HIV and AIDS. "…government should also involve older persons in HIV and AIDS related matters, and provide them with enough materials such as gloves, plastic aprons to protect themselves from becoming infected." (Case study # 1) One felt that the burden of caregiving would be reduced if the government supported carers by exempting them from paying school fees for orphaned and vulnerable children.

5.3.3 Discussion

An analysis of the data collected for the case studies showed that the respondents by and large reported similar problems and experiences relating to caregiving – both in urban areas and non-urban areas. The case studies ended when it became evident that no new information was forthcoming (see section 5.3.2) – in either the urban or non-urban settings. Hence, saturation was deemed to have been reached with the case studies. Content analysis of the data was then carried out, rather than using a grounded theory approach.

A distillation of the findings showed that HIV and AIDS affect older caregivers on several levels: 1) Caregiving compromises their mental and physical health; 2) they suffer emotional problems; 3) they must forego employment opportunities and thus livelihoods because of caregiving responsibilities; 4) they fear stigma and discrimination; 5) some hold fatalistic beliefs about the disease; 6) they contend that the government should support caregivers by providing financial support in addition to their old age grant; and 7) they appear to render care in anticipation that their grandchildren may reciprocate care and support in the future From a social exchange theoretical perspective, such anticipation is referred to as delayed reciprocity.

Some carers reported that the strain of caregiving resulted in new ailments, such as sleep disorders, constant headaches, stress and depression. Several suffered from physical ailments such as hypertension, arthritis and diabetes. Some reported health conditions that had not been diagnosed and/or were being treated by a doctor. Some feared antagonistic, or "harsh" treatment from health professionals at public health care facilities. Hence, emotional health problems that they suffered would conceivably be debilitating, and reduce their ability to render care and cope. Indeed, it is possible that the chronic health conditions that several carers suffered could cause physical disability and even lead to an early death.

Caregiving not only has a negative effect on an older person's health, therefore, but affects his/her ability to engage in income generation. Some carers reported that they had to give up their job to be able to care for the PLWHA and grandchildren full-time. Indeed, such a disruption in an older person's financial coping strategy could worsen his/her already vulnerable situation. Fear of HIV and AIDS stigma was common among the caregivers. Some reasons advanced for a fear of stigma were that people might gossip about the family,

because of “this thing” (disease) in the household. Even worse, grandchildren may be discriminated against, and their lives put at risk, or other children might not play with them, which would cause unnecessary misery for the children. Such fears indicate that HIV and AIDS related stigma does not stop with the PLWHA but affects all household members. Labelling HIV and AIDS as “this thing” indicates a frustration and a sense of helplessness of carers who carry the burden of caregiving.

The myriad problems presented by the epidemic and caregiving responsibilities clearly induced a sense of despair in the carers. Some held fatalistic beliefs about the disease, possibly as a way of coping, such as AIDS being punishment from God to wrong doers, and only God being able to bring a solution to the problem of AIDS. Such utterances may indicate a desperate need for support and counselling.

There were no discernable differences in caregiving patterns and problems between caregivers in urban settings and their non-urban based counterparts. However, it was evident that the carers could not cope with the burden of caregiving on their own and needed formal support. Some suggested, for example, that the government should consider exempting older caregivers from paying school fees for their school-going grandchildren. In the absence of formal support, older carers cope with their burden as best they can; the degree of informal support they receive is variable, but support that some receive from NPOs is fairly considerable. They were of the opinion nonetheless that they now need formal support commensurate with the caregiving demand on them. Thus, by implication, if caregivers are sufficiently supported, they will be better able to care for affected grandchildren until they reach independent age.

Hence, older carers interviewed in the case studies demonstrated by their actions that they have a contribution to make as partners in the fight against HIV and AIDS – if they are secure, have improved self-esteem and feel confident. The carers demonstrated their resilience and compassion, but they were buckling under the strain of caregiving and the pain of not being able to provide adequately for their grandchildren. Nonetheless, NPOs, according to the carers, do commendable work to ease the carers’ situation: especially in providing information and training on HIV and AIDS, transferring skills carers, and supporting carers emotionally and materially.

PART 3: KEY INFORMANT INTERVIEW DATA

5.4 ANALYSIS OF THE KEY INFORMANT INTERVIEW DATA

5.4.1 Introduction

Eight persons were identified as key informants in the three provinces, on grounds of their knowledge of government policy and planning on HIV and AIDS, and were interviewed by the researcher using a specially constructed interview guide. Of the eight informants, five held positions in government and three managed an NPO that served older persons. In each province, two senior government officials in provincial departments of Social Development and Health, respectively, were identified, but one was unavailable for an interview as agreed. Interviews were then consequently conducted with only five government informants.

The data from the key informant interviews were analysed in the following domains: 1) Knowledge of and availability of policies and programmes to support older caregivers; 2) the role of the provincial government department or NPO in providing support to caregivers; 3) older persons,' or their representative bodies' participation in policy formulation processes; 4) their participation in the monitoring and evaluation of implementation of policy recommendations; 5) the availability of resources to facilitate older caregivers' participation in the development and implementation of HIV and AIDS policies and/or strategic plans; and 6) the informants' opinions on how national policy makers can enable district managers to coordinate activities at a local level in order to support older person households affected by HIV and AIDS. Opinions of the informants and issues which they identified that were prominent in the data, when analysed, are discussed below.

5.4.2 Analyses of data from interviews with government informants

5.4.2.1 *Knowledge and availability of policies and programmes to support older caregivers*

The informants were asked how knowledgeable they were of policies and programmes to support older caregivers affected by HIV and AIDS. Most seemed puzzled that there should be a need for specific policy and programmes in this regard. An informant commented that: "…we work on the basis of guidelines on the HBC (home based care) programme …there are organisations of older persons [that] the department supports…" Hence, such problems according to this informant, were being met sufficiently by programmes such as the HBC and

there was no need for a specific official policy framework to address older caregivers' support needs.

All of the informants indicated that their department has no specific policy to address older caregivers' needs. Nonetheless, a range of opinion on policy intervention to support such needs emerged in the interviews. An informant went to the extent of shifting the responsibility for such intervention to other departments. She commented: "This [older caregivers' vulnerability] is a Social Development [ministry] function. Our department's role is to implement the national strategic plan and policy on HIV and AIDS. I cannot say much on this." Another informant pleaded ignorance on the part of her department of problems faced by older caregivers: "… our department has [only] recently become aware of this problem ….there are no strategies nor policies that have been conceptualised to date to address this issue."

Most informants referred to other mechanisms used or followed by provincial governments to address older persons' needs in general, among which are legislation that provides for the social old age pension and foster care grants, and guidelines for home based care programmes. There were however, the informants explained, no specific mechanisms to support older caregivers. From what could be gleaned in the interviews, the provincial departments seemingly do not see an urgency to address the effects of HIV and AIDS on older carers in a co-ordinated manner; quite simply, the responsibility was shifted to other department(s) or to non-profit organisations.

5.4.2.2 *Role for government departments to support older caregivers*

Most informants acknowledged that there could be a role for their department to provide support to older carers. An informant in KwaZulu-Natal indicated that her department had established and was supporting luncheon clubs where food is provided as well as an environment conducive to socialisation among peers. Her department also provided care to orphaned children by offering caregivers respite in the mornings. Some informants viewed older persons not only as support recipients, but also as a resource in the community and their household. An informant in the Western Cape indicated: "Older persons are a very important support system, and a resource at community level in terms of caregiving to young children… but they need to be capacitated by government about the HIV and AIDS

problem." The informant continued: "Older caregivers can be of use in supporting other older persons who are in the same situation [caring for PLWHA and OVC]."

An informant in the Eastern Cape suggested that her department could play a role by offering life skills development and adult basic education. An informant in the Western Cape identified a role for her department in "upskilling" older caregivers to help them to render better care to their charges. She argued that older carers' role could be expanded to benefit the community as a whole. They could be used as counsellors to infected and affected persons. An informant in the Eastern Cape pointed to an information and education gap in the current support mechanisms provided by government for older persons. He said: "…clearly there are no targeted programmes to meet the support needs of older caregivers. Some provide care to PLWHA and have no knowledge on how to protect themselves against infection. They urgently need information and education." An informant in the Western Cape suggested that the government should find ways to provide financial support to older caregivers, especially those who are destitute (as a consequence of HIV and AIDS).

5.4.2.3 *Putting older caregivers' support needs on policy agendas*

The informants expressed diverse views on how older carers' support needs may best be placed on policy agendas. Most suggested that older carers should mobilise themselves, or form community groups so that their voices may be heard collectively. The informants felt strongly that a solution to older carers' difficulties lay within the carers' power. One informant commented extensively:

You see, within the structure of the Western Cape Province Department of Health there are [sic] the Multi-sectoral Task Team [MSAT]. These structures have representatives from community organisations, the Department of Health, the Department of Social Development, non profit organisations such as Treatment Action Campaign and others. MSAT provide (sic) a forum, maybe an opportunity for grassroots organisations to put their case to government officials. This is a forum where older persons and their organisations can make their voices heard, to channel their concerns up to province and national government. Older persons can also link up with vocal and organised NPOs such as TAC so that their voices can be readily heard. But older persons need to belong to well organised structured organisations to which government can provide support.

An informant in the Eastern Cape echoed this view: "I think they must belong to well structured organisations so that government can interact and exchange views with them on policy issues."

Another view expressed was that the government needed to engage with older carers proactively, as it (the government) is aware of the many challenges facing older persons. Two views in this regard were as follow:

It starts with engaging them [older persons] as stakeholders. Through that, one gets to know what are their needs. However, policy does recognise that they need psychosocial support, need to be cared for, and need financial support. A programme for carers is needed. Poverty reduction programmes must be put in place for people who look after orphaned children and PLWHA. The programmes need to be sustainable, not only provide food parcels.

I think the Department of Social Development needs to raise the issue of older persons who care for PLWHA within government. Coupled with this are issues of poverty, health, abuse many older persons suffer and so on.

An informant in the Western Cape gave an alternative view: "I don't see any particular or specific way that their issues can be put on the agenda. I think when we [government] talk about HIV and AIDS issues it is assumed that everybody is involved. There is a lack of human resources to deal with these specific issues."

Overall, the government informants across the three provinces agreed that older persons are affected by HIV and AIDS and need to be supported. However, there was disagreement on how such support should be provided. Some felt that older persons should "stand up for themselves." Another viewpoint was that the government should raise the issues affecting older persons within government structures.

5.4.2.4 *Older persons' participation in the development of HIV and AIDS policy*

The informants were of the opinion that older persons should be involved in the development of HIV and AIDS policy. However, opinions were diverse on how their involvement should be realised. An informant in the Eastern Cape Province suggested that NPOs working with

older persons should advocate and lobby government to include issues of older persons caring for PLWHA in policy and programme development processes. Other informants felt that existing government initiatives should be used to draw older persons into the processes. An informant suggested that: "They [older persons] can be involved through existing programmes such as LoveLife, where they have projects such as gogoGetters that show the potential that older persons possess to combat the scourge." Another felt that: "... older caregivers must be invited [by government] to stakeholder meetings. We need to identify where older people are, for example, in churches, older persons' club, *stokvels*, old age homes, and engage them, find out what they need. We need to piggyback on what is already there, such as Golden Games, and incorporate HIV/AIDS issues. Their ideas can be accessed this way..."

Two informants were adamant that it rests on older persons themselves, or their representative organisations to find ways for them to become involved. An informant in the Western Cape Province explained:

The way policy develops is through community structures, for example, sex workers, disability groups, trade unions and so on. These structures bring their issues to the table for debate. Older persons need to start their own groups to voice their policy needs or join hands with other well established NPOs so that they can be invited to the policy formulation process. Strangely enough, there are no older person representatives involved in this process [from the province's HIV/AIDS directorate].

Following a similar line of reasoning, an informant in KwaZulu-Natal Province pointed out that: "... they [older persons] or their representatives must attend community forums to put their issues on the policy agenda."

5.4.2.5 *Barriers to older carers' participation in policy development*

Informants expressed contradictory views regarding barriers that inhibit older caregivers' participation in policy formation processes. Some pointed to internal problems in older person organisations, such as poor management structures, and to some NPOs being territorial and unwilling to share information with like minded organisations, as well as to a lack of creativity on their part. (An unwillingness of NPOs to work with each other has been

identified in the literature (International AIDS Alliance, 2002; Jackson, 2002).) Other informants felt that a major barrier was government bureaucracy.
An informant who felt that barriers stem from within the NPO fraternity, which was in disarray, and explained:

One critical issue or barrier is the disorganisation of older persons organisations, especially in rural areas. Maybe in urban areas this is better. Older persons need a platform nationally that organizes them and gathers their concerns. Also what is needed are platforms that function provincially and at district level were most of their day to day challenges happen or can be identified and addressed immediately. At a conference held here in the Eastern Cape in 2005 the issue of districts for a ..... [inaudible] *was hinted at and needs to be taken forward.*

Regarding NPOs being territorial and unwilling to share information, an informant in the Western Cape stated: "... we would like to have more of them and their organisations participating across the province doing work…. but they don't want to go to other areas. ….challenge is to roll out their work. NPOs don't want to go to other areas. The territorial mentality or attitude among organisations is another barrier."

Another informant who viewed a lack of creativity on the part of older person NPOs as a barrier suggested ways to involve older carers, or access their ideas on caregiving. He explained: "...also people are not innovative, they want to do the same old things other NPOs are doing. For example, involving older persons in artistic [sic] forms of knowledge or information." He suggested that NPOs need to explore other ways to disseminate knowledge and information on HIV and AIDS, such as oral history and story telling, at which most older persons are good.

Government "red tape" was perceived to be a major obstacle. An informant in the Western Cape Province stated: "It is not easy for NPOs or individuals to know who to talk to in government. Government departments are huge and bureaucratic. It is easy to submit one's concerns to the wrong person or level or department and this results in people's submissions getting delayed or even lost in the bureaucracy." An informant felt that stigma and ageist attitudes on the part of government officials are barriers to older persons' participation in policy development processes.

5.4.2.6 *Removing the barriers*

Regarding how the barriers to older carers' participation in policy development processes may be removed, some informants felt that it was the government's responsibility to facilitate older caregivers' participation and pointed out that the government needed to find the resources (both human and finance) to facilitate such participation. Others felt it was older persons' responsibility to fight and overcome the barriers themselves. Regarding the view that the government should take responsibility, informants explained as follows:

One thing that needs to happen from a government point of view is that we need to improve inter-departmental capacity and co-operation in addressing older caregiver issues. Government needs to engage NGOs that work with older persons and understand their concerns. Also parliamentarians need to look into this issue when they do consultation in public forums or constituencies.

If one [government] finds things as important or critical you provide finances and human resources to match those priorities, even more so if policy imperatives are such that this sector is important. Your budget needs to be aligned with your objectives with things that are critical and important. We have indicated in our operational plan we will be working with older persons in this financial year as a special sector in relation to HIV/AIDS. We intend to lobby and advocate for a HIV/AIDS dedicated post… personnel or coordinator at district level. We can only provide services properly that way particularly to older persons.... A specific person from the Premier's office has been appointed specifically to look at problems faced by older persons. The Department of Social Development can't do this, it is overstretched.

Regarding older persons taking responsibility to overcome barriers inhibiting their participation in the policy development process, an informant argued that: "Well, essentially [they] need to lobby or advocate hard to make their issues heard. They need to use the media and civil society structures, and build a strong momentum about their cause. Older persons need to be more vocal and visible to be able to overcome the above barriers."

Despite some informants' acknowledgement of a need for the government to involve older persons in the policy development processes as a whole, the informants felt constrained by a

lack of resources, and a lack of co-operation and/or policy action and co-ordination between departments, in what they can achieve. An opposing view abdicated government from taking responsibility to facilitate older carers' involvement and remove barriers to their exclusion.

5.4.2.7 O*lder persons' or their representative bodies' participation in monitoring and evaluation of policy implementation*

Regarding older carers' participation in monitoring and evaluation of policy implementation that affects them, perceptions among the informants were by and large similar. A general view was that older persons' participation need not be treated separately from the participation of other interest groups. A consequence of this attitude had resulted in older persons not being included in monitoring and evaluation processes. Comments in this regard were as follows:

Oh well, the monitoring and evaluation is not specifically focused on older persons roles per se, but looks at the general performance of non government organisations contracted by government …. Chances are that policy developers do not put emphasis on older persons' issues. Maybe more emphasis should be put on older persons challenges by HIV/AIDS policy and programme developers. This area needs serious consideration by government policy makers.

We have not really thought about older persons as such. We do not make a distinction in terms of what age group does what. We have never focused our minds specifically on the role of monitoring and evaluation of HIV/AIDS policy.

One main reason that I can think of is the lack of capacity in the department to concentrate on a specific section of the population. Also one does not want to encourage a linear approach to social problems owing to a lack of resources on the government's side.

This disregard, as would appear above, of the rights of older caregivers or their representative organisations to participate in policy monitoring and evaluation is discriminatory and implicitly indicates discriminatory attitudes on the part of government officials. An argument that a lack of resources prevents the government from addressing older persons' policy needs is negative discrimination, as resources are available to address the needs of other population groups such as children and the youth.

5.4.2.8 *Availability of resources to facilitate older carers' participation in the development and implementation of HIV and AIDS policy*

Most informants indicated that there was a lack of resources to facilitate older persons' participation in the development and implementation of policy and strategies on HIV and AIDS in their departments. Some indicated that resources might be available from the government's side, but seemed to confuse such a need with resources available to support older persons' material needs such as food. One informant felt that it was not her department's responsibility to make resources available for such activities. An informant explained:

Yes, there are resources available, for example, finance from the National Conditional Grant. However, the grant does not look specifically at older persons' issues in relation to HIV/AIDS. Older persons are catered for as part of the broader community and are not targeted as a specific group.

However, the informant contradicted himself by adding*:* "We [government] fund different sectors in the community, for example youth, creative arts, and so on. Therefore, older persons' organisations are also funded in this way."

Two informants on the other hand stated that the government does not make resources available to facilitate the involvement of older persons in policy development and implementation. An informant in the Western Cape Province explained:

Well, yes they [resources] could be made available if we thought about it carefully and strategise accordingly. But it is something we have never considered an issue. The reason is that we don't know much about older persons. Normally, resources are directed where government knows about the problem or issue. For example, homeless children, orphans, HIV/AIDS among the youth and so on.

An informant in the Eastern Cape Province stated:

No, not really. But as far as I know, an organisation called Age-in-Action does engage and mobilise older persons around such issues [resource mobilisation] nationally… I think the availability of resources is a matter that will require lobbying of government ministers,

joining of hands by various bodies concerned by older caregivers' issues. Also there is a need to pool resources together by the various role-players and make an integrated approach in making such resources available.

One informant felt that it was not her department's responsibility to make resources available and shifted the responsibility for such activity to another department, saying: "The Department of Social Development could make them [resources] available, not our department."

Thus, different government officials hold different views and understanding of the availability of resources and making them available to facilitate the involvement of older carers. Their views ranged from being ignorant of older caregivers' needs, to viewing and shifting the role of mobilising resources to other government departments and non profit organisations working with older persons.

5.4.2.9 *Informants' opinions on policy makes' enablement of district managers to co-ordinate activities to support older carers*

Most informants were of the opinion that national government policy makers need to capacitate district personnel through training in the implementation of policy measures. An idea of involving local or district personnel in the policy formation process that would ultimately affect the way they function was deemed unimportant. Most informants perceived policy development to be what Walt (1994:156) has referred to as a "linear" process, where policy formulation is seen as separate from implementation. Thus, policy making is interactive, and formulation and implementation of policy are two elements in a continuous loop (Walt, 1994:156-57). Nevertheless, with the exception of two informants in the Western Cape Province, who understood the importance of district officials' involvement in the entire policy formulation process, which would benefit local role players and communities affected by the scourge explained the process of policy formulation as follows:

…it works in two ways. There is a pathway up, this path facilitates the channelling of community needs to government via structures such as MSAT. One can consider this as a sort of district level body. The information from this level is then channelled to the provincial level which in turn channels the needs to national level. If national agrees that the needs are

real or based on facts then policy is formulated at national level, and then this is channelled back to the province. Provinces then develop programmes to implement the policy that will address the problem. Sometimes, provinces and local government may have powers to develop their own policies. However, a major problem is that provinces and local government do not have their own budgets. Money comes from the national government.

…it's a bottom up approach to policy making process. There needs to be decentralisation of power; more resources need to be put at local or district level. It will be much easier to co-ordinate, disseminate information timeously. More structures, for example local AIDS co-ordinating committees, need a body that will look at older persons' issues. These structures allow engagement with older person and their organisations.

On the other hand a view of district officials as implementing agents appeared to be strongly embedded. An informant explained:

I think a strategy needs to be devised by government such as the inter-ministerial committee [national level], and look at what the policy is saying, whether they are explicit in terms of talking to the issues of older caregivers. If the policy does talk to older caregiver issues, then they must check whether the policy provisions are implemented at district level. If they are not, then government will have to capacitate district officials to implement the policy.

Another informant held the following view: "Officials at local level will have to be trained on how to work together with older persons and their representative organisations at district level. Facilitating forums between district management and older persons' NPOs must be created to perform this work." Yet another informant felt the only way to address the problem was to strengthen what is already in place at district level. However, forgetting the limited resources that officials at district level must struggle with, he said: "It is by strengthening the HIV/AIDS multi-sectoral forums operating at community level [that will serve as the voice of older carers on their policy needs]."

The informants therefore held opposing opinions, which may have been a function of their experience with policy formulation. Most policies that provincial officials deal with are formulated at a national level, or adapted from national policies. Hence, what was evident was a failure to appreciate the importance of involving district officials in the formulation of policy that would enable district officials to co-ordinate the activities of different role players.

5.4.3 Analysis of data from interviews with NPO managers

Data gathered from the interviews with three managers of non-profit organisations in three provinces are analysed below. All of these informants were female and middle-aged. One had trained as an occupational therapist, another was a retired professional nurse and a third was a retired teacher. Their years in practice ranged from 10 to 20. They had worked in public hospitals, public schools and/or non-profit organisations. The analysis is organised in four categories, which correspond broadly with the open-ended research questions put to them in the interviews. The four categories are: 1) Awareness of the national HIV/AIDS strategic plan; 2) accessibility of the HIV/AIDS strategic plan; 3) mechanisms to involve NPOs in monitoring and evaluation of policy implementation; and 4) facilitation of older person NPOs' involvement in HIV/AIDS strategic development.

5.4.3.1 *Awareness of the national HIV/AIDS strategic plan*

All three informants indicated that they were aware of the national HIV/AIDS strategic plan. However, only one stated that her organisation had a copy of the plan in its possession – somewhere in the office, but she was not able to find it immediately. Another informant replied: ''… we just heard the information from a local community meeting that a document like this exists." Hence, in all, the informants may not have been fully cognisant of the contents of the plan.

When the informant who stated that her organisation has a copy of the strategic plan was asked how she had obtained it, she replied: "I think I picked it somewhere. I picked it up at a launch of the strategic plan. It was a government called meeting, and then I picked it up."

It may be accepted that accessibility of government documents to lay persons is complicated, owing to bureaucracy, and ignorance of the existence of the documents and how to contact the relevant government department to obtain a document. When the three informants were asked whether their organisation had received an invitation to be part of the strategic plan formulation process, all replied negatively. An informant replied irately: "No, no, no, our organisation was never involved in any way in the development of this strategic plan you are talking about." The other two informants said they had not been invited, but had heard that meetings on developing the document were being held in their area.

5.4.3.2 *Mechanisms to involve NPOs in monitoring and evaluation of implementation of the strategic plan*

Monitoring and evaluation are an essential oversight function in policy implementation, and provide policy makers and managers with direct feedback on the implementation of a particular policy (Walt, 1994). The informants were asked whether monitoring and evaluation of the implementation of the HIV/AIDS strategic plan had had adequate mechanisms in place to involve NPOs in the processes of the national strategic plan. The informant who had read the document replied: "No, not at …well I can't say I noticed anything said on older persons, so I did not bother reading further about the plan… it did not address my area of interest, you see."

When asked about barriers to, or reasons for the non-participation of older persons in the development and implementation of the plan, an informant replied: "Ja, it all has to do with communication from the government's side which is problematic. There is poor communication from government offices to role players at community level." Another informant complained about the government's attitude towards older persons' difficulties compared to other sections of the population and stated: "[The] working relationship between government and older persons' organisations is not strong. Government does not regard older persons' issues very seriously compared to children's problems and the youth."

Reasoning similarly, an informant suggested: "I think the problem is more to do with not paying too much attention to problems affecting older persons and their organisations by government and business. For example, when we apply for grants for older persons looking after orphans we always get letters regretting or refusals to issue grants."

When asked how a relative lack of attention to older persons' needs could be remedied, two informants were unsure but offered reasons why the government possibly responds in the way it does: "Mh-h-mh, I would not know, maybe because government thinks older persons are no longer going to contribute in society anymore as compared to children and the youth. That is why."

Another said: "I… I… I'm not quite sure, because the problem is mainly with the offices in Home Affairs. For example, they will ask for all sorts of documents such as birth certificates, the death certificate of the child's parent. When one applies for these [documents] they take a

long time to be processed. Sometimes when they are successful, the person has already died or something like that."

Preferring not to sound judgemental about the government, an informant said: "Well, people in government responsible for policy development are interested in involving a diverse group of people including older persons, [but] then they need to invite representatives of the groups to participate in the process of policy development."

5.4.3.3 *Facilitation of older person NPOs' involvement in HIV and AIDS policy development*

When the informants were asked how the district or local government could facilitate the involvement of older persons or their organisations in future HIV and AIDS policy development to benefit older caregivers, all three agreed that the government must engage NPOs representing older caregivers directly, and suggested different mechanisms on how to achieve this objective. An informant commented extensively:

Well, number one, there needs to be somebody from the local office who is aware of policy planning who knows what is going on in provincial office and national office. That person needs to make it their business to invite and engage role players at district level in the plan and discussion of policy development. And then to be responsible enough to take matters to the next level. There is clearly no one at district office who knows what is going on at the upper levels as far as policy is concerned. Clearly, there is no one who plays that role at the moment. Officials at local/district level are busy with organising the day to day administrative duties such as organising social grants. No one is charged with policy development and or implementation. The organisation of role players to participate in these processes is very bad.

Another informant complained bitterly about the exclusion of older caregiver NPOs and said:

I, I, I think the offices [home affairs, social workers and others] need to be closer to the communities. We are isolated, we are not visited by government officials. We are not taken seriously as compared to other NPOs such as those working with orphans and street children …For example, we do not have money for transport to transport older persons to far away offices in the city. Government must involve us directly in these activities. We have

experience from working with poor and suffering people for more than five years …it is very difficult to receive funds from government, especially for activities to older persons affected by HIV/AIDS…

The third informant added: "Meeting with older persons' organisations such as ours must be organised by government social workers, where we can discuss together on how best we can share ideas on how to involve older persons and their organisations in the process of policy making."

Clearly, older person organisations are keen to be involved at a district level in policy formulation processes, as evidenced in the complaints that were levelled against the government's exclusion of older caregiver NPOs in these processes. However, the informants were not only critical of the government's approach or stance, but made suggestion as to how the situation might be corrected, to benefit their organisation's members. Suggestions made included the government's consultation of older persons' representative NPOs, and the appointment of dedicated district policy to facilitate deliberation between community organisations and government personnel at district level.

5.4.4 Discussion

In essence, both the government informants and the NPO informants agreed that no policies are in place to support older caregivers. Both groups identified a need for older persons or their representative organisations to be involved in policy development and implementation processes. Both proposed mechanisms through which these objectives could be realised. Although the government key informants were sympathetic to the inclusion of older carers in related policy processes, they were of the opinion that it is up to older persons or their representative organisations to organise themselves as a group and to participate in policy formulation and implementation processes. Government informants suggested structures such as the MSAT (Multi-Sectoral Task Team) as appropriate vehicles through which older persons could make their voices heard in policy development. However, these structures are largely unfamiliar to older persons' representative organisations, which suggests that they and their activities are poorly marketed by the government at a district or local level.

The NPO informants were less forthcoming on the matter of older persons' participation, mainly owing to a lack of information and their own low level of participation in policy formulation processes. They indicated that they were unimpressed with the way in which the government developed policy. All of these informants complained about the government's lack of consultation with organisations such as theirs. As a consequence, two of the three NPO informants were ignorant of the national HIV and AIDS strategy plan. The informant who knew about it was not well informed about its provisions. These informants felt that the government worked in a complex and bureaucratic manner, which made it difficult for older persons to participate in processes, or to submit their concerns and needs to the relevant government structure(s). Nonetheless, despite feeling excluded in policy development processes, the informants emphasised that older persons' representative organisations were willing to participate in these processes and that such participation would benefit their members.

Both groups of informants agreed that a structure or an individual was needed at the district level to serve as a policy co-ordinator, and as a link with higher levels of government and affected communities. This would facilitate the participation of older persons, their representative organisations, local government personnel and older caregivers themselves in deliberations, and ensure that their perceptions, experiences and needs were taken into account. Such an approach would fulfil a central principle of the UN' Principles for Older People, which encourages older people's full participation in all matters affecting their lives (UN, 1991).

PART 4: TRIANGULATION OF THE DATA

5.5 TRIANGULATION OF THE DATA FROM THE THREE SOURCES

Data collected from the three sources – a survey (Part 1), an in-depth interviewing study (case studies)(Part 2) and interviews with key informants (Part 3) – were analysed and the results shown and discussed above. These results are now triangulated to provide a comprehensive picture and understanding of the situation of affected older persons – from both a client perspective and a provider perspective. Triangulation combines the results of analyses of data gathered from multiple sources, possibly using multiple methods. In the present study, both the quantitative and qualitative research methods were used to gather data. Triangulation of

the results of the analyses will indicate the magnitude of the problem, from the perceptions of various role players and stakeholders, and what solutions in the form of policy and intervention may be desirable and feasible.

As indicated in Chapter 4, triangulation is used as a tool 1) to confirm, cross validate and corroborate results obtained from the use of one analytical technique with those obtained from the use of other analytical techniques (Green, Caracelli & Graham, 1989; Poundstone et al., 2004), and 2) to strengthen overall findings. In the present case, information obtained from the case studies was corroborated with survey data, in specific domains, by comparing the two sets of data and identifying areas of concurrence or divergence in the data. In general, the information obtained in the case studies corroborated that from the survey, and *vice versa*. In addition, the case studies yielded information, not solicited nor recorded in the survey, an analysis of which served to enrich an understanding of the carers' situations.

The strength of the survey data lies in its description of the magnitude of the difficulties that older carers in the three provinces, in both urban and non-urban settings, face in day-to-day caregiving. The survey demonstrated a wide range of activities in which the carers engage in rendering care to PLWHA and OVC. The analysed survey data also yielded measures of the respondents' health status and, objectively and subjectively, the extent to which they need to be supported in order to reduce their caregiving burden. However, on their own, the survey data were unable to provide a full understanding of the caregivers' experience of caregiving, nor how they cope with the challenges of caregiving; such understanding, then, was achieved in the analysis of the case study data. That said, the case studies were only conducted in a single province (the Western Cape), and generalisation of these findings to settings in other provinces may be limited.

The case studies elaborated the perceived greatest difficulties the carers' experience in caregiving, because of their health conditions. Rather than mere self-reports of the presence of a health condition, the in-depth study findings indicated the nature of the illnesses, complications and new conditions that developed as a result of caregiving – such as sleeplessness, crying and a worsening of their diabetes. The carers were able to verbalise moreover reasons why they are unable to engage in paid employment, which they explained was because of their caregiving responsibilities. In addition, they were able to explain how they coped with caregiving under these circumstances. Some, for example, engaged in petty

trading, but for which they needed to borrow money from money lenders to purchase goods to sell, with lenders charging a high interest rate.

The carers were also able to express themselves on matters relating to HIV and AIDS. The majority, for instance, were knowledgeable about the disease, but some believed that infection with the virus is punishment from God – which finding concurred with the survey data. Finally, the case studies enabled carers to articulate their experience of AIDS related stigma. For some, the fear of gossip, discrimination and violence against their families by some community members was uppermost in their not disclosing the status of an infected person in their household.

A contradictory finding in the analysis of the in-depth study data was that some carers feared "harsh treatment" from certain health professionals at public health service points. By contrast, the survey data analysis indicated a notably high level of satisfaction with services and treatment at these facilities. The in-depth interviews therefore afforded the respondents an opportunity to verbalise some of their experiences more thoughtfully and frankly than by merely responding to fixed-response items in the survey questionnaire.

Data obtained from the government key informants suggest that a major gap exists between the challenges and hardships that caregivers face and the level of understanding of the government of their challenges and hardships. Consequently, the government's responses to older carers' support needs have been inadequate or non-existent. Indeed, the government key informants appeared more concerned about denying that it was their department's responsibility to involve older carers and/or older persons' organisations in policy processes that affect carers. Rather, they blamed bureaucracy for a lack of consultation and inclusion of these stakeholders, and tended to shift the responsibility to older caregivers and NPOs. By and large, the government informants appeared to be unaware of how desperate the situation and plight of older carers are. By implication, they appeared to expect that older carers, triple burdened by caregiving, poverty and their poor health, should themselves take responsibility for making their voices heard. These informants overlooked the carers' vulnerability on several levels: one being the carers' low level of education and inability to articulate their needs and demands, and another being their lack of knowledge on how government structures work and how to access them.

Ageist attitudes on the part of some of the key informants were seemingly an underlying problem in their lack of understanding, sympathy and response. Some advanced an argument that the government lacks the capacity and resources needed to attend to the needs of a specific section of the population, i.e. older persons; yet the government promotes and supports programmes targeted at the youth, the homeless and orphaned children. Ageist attitudes of some government informants were highlighted by an NPO informant, who alluded to the perception of government that older persons are a spent force and no longer contribute to society. A lack of consultation with older persons' representative structures is further evidence of ageism and age based discrimination against older persons. Again, a lack of support from the government indicated by the survey respondents (in Part 1) is confirmed by a lack of knowledge about caregivers' needs acknowledged by some government key informants (in Part 3). Nonetheless, a positive sign is that some government informants showed a willingness to involve and work with older persons' structures as a way to address older carers' needs.

Despite not being consulted on issues relating to HIV and AIDS intervention, as pointed out by the NPO informants, older caregiver NPOs steadfastly work and support older caregivers, as evidenced in findings in the case studies (Part 2). The majority of these survey respondents reported that their knowledge and information about the disease was acquired through an NPO. In addition, some reported they receive material assistance, acquire income generation skills and enjoy broad support from an NPO on an ongoing basis. The anomaly of government not working with NPOs, which have first-hand information on and direct contact with older caregivers, cuts across all three provinces. The government's lack of consultation with NPOs in effect disempowers the organisations, and these informants expressed frustration and a sense of helplessness (Part 3). Similar frustration with the government's functioning was expressed by respondents in the case studies, who referred to the inordinate time that government bureaucracy takes to process and approve an application for a grant.

The above interpretations of the triangulated data aside. Some minor difficulties encountered in interpreting this data warrant mention and indication of how they were overcome. The first difficulty was combining and integrating three data sets of hugely different proportions: The survey data (n = 305), the case study data (n = 10) and the key informant interview data (n = 9). Moreover, the case studies were conducted in only a single province. In addition, the survey data comprised mainly responses to structured items, whereas the data of the other two studies were responses to open-ended items. The combination, comparison and potential

correlation of some data in three data sets could have been inherently problematic. However, this problem and other problems were solved as follows:

A first problem was that of the researcher's subjectivity and consequent bias in the interpretation. Such bias could have entered through his disciplinary orientation and cultural experience, and his knowledge of the study context. In interpreting the data, the researcher had to guard moreover against slipping from facts and data to inferences – some inferences possibly unsupported by the data (Levinson, 1994: 43). I therefore endeavoured to cite the facts in respective data sets from which inferences were made. Similarly, I endeavoured to genuinely represent the respondents' views and circumstances, and to not select issues of concern or interest to him. Additional steps taken to ensure that interpretation remained objective included i) engaging in self-reflection (Burns & Grove, 2001), in order to be aware of potential biases and avoid them, and ii) presenting the triangulated data and his interpretations to his supervisors, as mentors, for scrutiny and affirmation.

A related problem was how the researcher should provide an accurate account of the information and interpretation. In quantitative research, verification of the accuracy of such reporting may be conducted through "debriefing" between the researcher and the study participants (Berg, 2001). In the present study he used a triangulation strategy *de facto* to verify the accuracy of his reporting and interpretation. The strategy helped him moreover to identify instances of convergence and/or divergence in the data sets.

Finally, the researcher had conducted the ten case studies and documented the participants' experience in the field himself, which provided him with a firsthand and in-depth understanding of the phenomenon under study; he was able therefore to communicate a detailed and credible account of the study settings and the carers' situations. This information and interpretation could be effectively employed in the triangulation of the case study data set with the survey data set. However, more problematic was the triangulation of the key informant data with the data and findings of the other two data sets, but largely for reason of the informants' relative lack of understanding of the carers' situations, and the paucity of government responses and a strategy.

In summary, the evidence presented from the analyses of the data from the three sources

validates the need for policy development to support affected older carers, in order to reduce the effects of the epidemic and to ameliorate the care burden of the epidemic on their well-being. A policy framework, informed by the evidence of the older carers' situations, and gaps in responses, as identified in the multiple datasets, is developed and proposed in Chapter 6. The policy framework will aim to guide stakeholders towards the development of strategies and responses that ensure the welfare and health of present and future cohorts of older caregivers are sustained, through expanded provision of formal support and support of the activities of non-formal service agencies.

5.5.1 Theoretical view of the results

The study results presented and discussed in this chapter, and triangulated in the sub-section above are predicted by the theoretical framework used in the dissertation. From a feminist theoretical perspective, and taking into account that older women constitute the majority of older caregivers to PLWHA and OVC, who thus carry this burden, they were found to be markedly disadvantaged and marginalised when it comes to support and counselling. The low level of recognition of the onerous task of caregiving in this case may be attributed partly to a patriarchal societal attitude that caregiving is a "natural" task for women – who are viewed as nurturers, not providers (only men are providers). What is significant moreover is that other than older women constituting the majority of informal carers, the large number of (non-formal) NPOs working against HIV and AIDS are primarily co-ordinated and managed by women as well. However, in the case of older women, who lack power through a low education level, few financial resources, and few political connections, as well as their low status in a patriarchal society, they are at risk of becoming isolated and their limited resources being over stretched. It is evident from the analysis of the data in this dissertation that the HIV and AIDS epidemic presents severe socio-economic and psycho-social challenges for the carers, female caregivers in particular, which then calls for gender and age specific interventions. An understanding of the partriarchal society in which these women live and care is thus similarly important in the design and implementation of appropriate interventions (Arhihenbuwa, 2003).

In conjunction with a feminist perspective on caregiving, a social exchange theoretical perspective has provided for an understanding of the underlying reasons for and dynamics of caregiving by older persons. Although social exchange theory argues a case for reciprocity

within dyads (of caregivers and care recipients) and within social networks in which care is rendered, this reciprocity may be immediate or delayed for the future, owing to the inability of one actor to reciprocate because of a disadvantaged position. In the case of the present study, OVC are not in a position to reciprocate what the caregiver provides immediately, but the caregiver may anticipate reciprocal care and support when she (or he) is old and possibly frail and in need of care and support. Hence, social exchange theory is unable to predict exchange reciprocity in this case

Following on the perspectives employed for viewing and making sense of the data and the findings, it is evident that planned interventions should be age and gender sensitive. In addition, interventions should link with caregivers' social networks and support systems, such as NPOs, churches, clubs and burial societies to which they belong, or are operated in their communities, to restore reciprocity.

CHAPTER SIX: A POLICY FRAMEWORK TO SUPPORT OLDER CAREGIVERS AT THE DISTRICT LEVEL

6.1 INTRODUCTION

It is well known that government policy makers are frequently unresponsive to empirical evidence on situations that should be remedied, sometimes through a lack of political willingness, or because of other priorities in the allocation of scarce resources**.** Feldman et al. (2001: 312) have suggested**,** tongue in cheek, that, "Researchers are from Mars, policy makers are from Venus." Nonetheless, researchers should be undeterred by policy lassitude, and proceed to produce and provide evidence-based information on the experiences of affected groups, with an intention to inform government policy and action. The uptake of such pertinent evidence by policy makers and its translation into policy and practice, however, may be poor – owing to a need to respond to the competing demands of multiple interest groups. Richardson and Jordan (1982) have referred to an "over-crowdedness of [the] policy environment," which makes decision making difficult.

Information gained from the empirical study as well as a review of the relevant literature and policies presented in this dissertation describe the magnitude of the problem of the effects of HIV and AIDS on older persons and their support needs, where they are caregivers to affected family members. The information includes characteristics of the affected group, and provides an understanding of the obstacles that carers in both urban areas and non-urban areas face. The findings indicate indirectly how various affected and vulnerable sub-populations (grandchildren, adults and older persons) might benefit at a household level from relevant policy and action aimed at mitigation of the effects of the epidemic on older caregivers.

Indeed, intervention aimed at benefiting all affected members of a household is indicated. Although older persons carry the greatest responsibility of caregiving in households where adults are ill or have died as a result of AIDS, in some cases care is being provided by orphans who are in truth too young for this responsibility. The two sets of caregivers face similar and different challenges. Orphan caregivers face several constraints, especially if their parents died as a result of AIDS (Ntozi et al., 1999). They and their siblings may face hunger on a regular basis; other vulnerabilities include facing an uncertain future regarding their

custody and sometimes having to drop out of school to take care of siblings. Some are dispossessed of their parents' property (HSRC, 2002; UNICEF, 2004). The caregivers' roles are similar however in that both are providing care at a time that is out of synchrony with their age: older persons may have expected to have "retired" from caregiving responsibilities; orphans are too young and lack experience to care for others on their own. Another similarity is that both are vulnerable: orphan carers lack the protection of their parents; older carers may suffer ill-health, and may be without a partner and their adult children may have moved away. Both sets of carers are at risk moreover because of the impact of poverty on their lives. What differentiates the sets however is that older carers no longer have the stamina to care and may be burdened additionally by compromised health.

In this chapter, pertinent evidence gained from the empirical study is presented to support the development of a framework to inform new policy formation and programme design and implementation aimed at supporting older caregivers at the district level. In addition, gaps identified in chapter 3 with respect to government instruments' inability to address some needs of older persons, such as the provision of dedicated health services at district level, are focused upon. The chapter is organised in six subsections: 1) A brief overview of the relevant literature and extant policy, as reviewed in chapters 2 and 3, and an elaboration of a rationale for a policy framework. 2) An interpretation of the study findings within a policy and institutional context. 3) An interpretation of evidence from the case studies and key informant interviews for their policy implications. 4) An outline of a policy framework. 5) A plan of action for the formulation, adoption and implementation of new policy and programmes to support older carers at the district level. 6) An identification of additional information needed through future research in this area.

6.2 LITERATURE AND POLICY REVIEW OUTCOMES, AND A NEED FOR A POLICY FRAMEWORK

The review of the literature on HIV and AIDS and older carers in Chapter 2 identified main issues relating to caregiving and the carers' situations in developing country contexts, specifically within Southern Africa. Older carers not only suffer chronic poverty, but experience unresponsive and inadequate health care services, difficulties in caring for young children, unsatisfactory living arrangements, specific challenges in rural settings, disrespect for their human rights and stigma as well. In addition, they are systematically marginalised in

HIV and AIDS interventions. Many report experience of negative and discriminatory attitudes from community members and health service providers (see WHO, 2002a; Knodel, 2006). The majority fear for the future of their children (PLWHA) and grandchildren, should they (the carer) die first.

A contemporary concern in developing countries is the increasing number of older persons who are themselves at risk of infection with the HI virus, either as a consequence of caregiving or poor reproductive health behaviour and care (CSO, 2008). Moreover, older persons are typically assumed to be sexually inactive, and less likely than young people to be at risk of contracting the virus; as a result, infected older carers are less likely to present to a voluntary counseling and testing (VCT) centre, or be encouraged to do so, for diagnosis and treatment. Nonetheless, irrespective of being affected or infected, older persons play valuable roles in their homes and communities as frontline carers, peer educators and counsellors (HelpAge International, 2005c). Hence, support interventions to mitigate the effects of HIV and AIDS on individuals and communities need to take into account the interdependence of affected groups: PLWHA, OVC and older caregivers alike. Of crucial importance is the development of a comprehensive policy framework aimed at the support of older carers – in their caregiving responsibilities, and to enhance their own health and well-being. Of equal importance is that programmes designed and implemented to support older carers ensure that responses to the epidemic occur in a co-ordinated manner, and are inclusive of all stakeholders.

A need for a policy framework to support older caregivers is proposed based on the review of relevant policies in chapter 3. The review found that relevant policies and their implementation are largely sectoral; responsibility for policy formulation is vertical and compartmentalised; and older persons and their representative organisations are hardly mentioned or involved in policy development processes.

The implementation of the South African government's strategic plan on HIV and AIDS is by and large left to NPOs. Government intervention such as prevention campaigns and support focuses on the youth and orphaned children, and overlooks, the effects of the epidemic on older persons. A mindshift and policy reformulation are therefore indicated. A major goal of such a shift in focus, should be the promotion of a strong district level strategy and the

capacitation of district level personnel, to be inclusive of older persons' needs as identified in this dissertation and the empirical study.

6.3 SURVEY OUTCOME AND THE IMPLICATIONS FOR POLICY

The survey outcome provides empirical information to inform responses to the diverse support needs of the carers. Key outcomes of the survey in this regard are as follows:

1) The financial situation of the carers and their household is obviously dire. Apart from social pension income (in the majority of cases) and income from child support grants (in a few cases), older carers receive little or no additional financial support. Although formal social safety nets are available to most carers, the resources they provide are insufficient, and are simply not designed to support caregivers faced with the complex and costly demands of caregiving. Older carers need dedicated social protection in the form of a specific PLWHA caregiving grant (see e.g. HelpAge International, 2004b) - separate from the existing generic caregiving grant, to help them to meet caregiving related expenses, for which no provision is made at present.

2) The majority of caregivers have particular vulnerabilities as a consequence of historical disadvantage and inequity, their low socio-economic status, their relative lack of access to resources, little formal support and the burden of care. The low levels of education of the carers, for example, limit their ability to access and use resources provided under the country's constitution. Hence, consideration should be given to improving older persons' access to adult basic education outreach programmes, especially in rural settings.

3) The carers in the survey reported poor health generally. The burden of caregiving was found to aggravate existing health conditions and to contribute to new conditions. Programmes to protect and improve carers' own health could help additionally to enhance and safeguard the health and well-being of dependent household members, such as grandchildren.

4) The majority of the carers were knowledgeable about AIDS: its causation, and who is at risk of contracting the disease and how. By implication not only may older carers be

amenable to participation in education and training programmes aimed at combating the epidemic, but they also constitute a resource that should be supported and included in policy development and implementation processes (see UN, 2004a).

5) Non-profit organisations play a key role in providing support to older carers and their households, specifically through training on HIV and AIDS, advice given on day-to-day caregiving, skills development and financial support. NPOs should therefore be included in an integrated and multisectoral approach to improve the situation of older carers.

6) Disclosure of the HIV and AIDS status of an individual within a household and stigma relating thereto are clearly difficulties with which older carers must cope. Stigmatisation of the disease persists in the carers' communities, and negative attitudes towards affected households and family members were found to be a serious obstacle to carers' ability to access help resources. Nevertheless, family members were found to be a strong source of support to a PLWHA, and a policy framework should therefore include recognition of families as a resource in efforts to reduce stigma (see UN, 2004a).

6.4 EVIDENCE AND POLICY IMPLICATIONS FROM THE CASE STUDIES AND KEY INFORMANT INTERVIEWS

Evidence from the case studies not only corroborated the survey outcomes, but provided additional information on the physical and mental health and effects of a loss of earning capacity of the caregivers. The multiple strains on the caregivers diminish their capacity to cope and to nurture grandchildren in their care. Although most were knowledgeable about HIV and AIDS, some carers nevertheless displayed confused and fatalistic beliefs about the disease, which suggests that more needs to be done to educate and correct misconceptions among a section of this population. Desperate for a cure for the PLWHA, and through confusion, some carers seek help from traditional healers and incur enormous expenses in the process. Some carers fear abusive treatment from health professionals at public health care facilities, which calls for mechanisms to be put in place to inform and educate health providers on the consequences of intimidating older carers, and PLWHA and vulnerable orphaned children whom the carers take to public facilities for health care.

The case studies also highlighted the coping mechanisms of older carers in dealing with their dire household financial situation. Some borrow money from money lenders who charge high interest rates and in some cases illegally confiscate a borrower's identity documents as surety against the loan. The range of coping strategies of the carers indicates their capabilities but also that they need formal support from the government.

The government key informants, by and large, understood a need for older persons, or at least their representative organisations to be involved in policy development processes, even though they tended to shift the responsibility for doing so elsewhere. The NPO informants criticised the top-down approach in policy development as non-consultative and exclusionary, and lacking in transparency. They highlighted the complex and bureaucratic manner in which the government works, which creates barriers to the participation of interested parties. Nevertheless, although the NPO informants felt alienated from policy development processes, they were keen to engage in policy development and felt that such participation would benefit their members. The UN General Assembly Special Session on HIV/AIDS (UN, 2001) has called upon governments to develop or strengthen strategies, policies and programmes which recognise the importance of the family in reducing vulnerability and coping with the disease. However, without the involvement of older persons or their representative organisations in policy mechanisms to address their problems, such provisions will remain empty words. Relevance of the evidence from the key informant interviews for the development of a policy framework is considered further below.

6.5 A POLICY FRAMEWORK TO SUPPORT OLDER CARERS

The policy framework proposed here is a response to that call, and is intended for use by government policy developers, non-profit organisations and other role players in this field. In line with the UN policy framework on HIV and AIDS and family well-being in Southern African countries developed earlier (UN, 2004a), the framework developed in this dissertation could serve as a mechanism for role players to use in order to review, analyse and reformulate existing policies and programmes. Support for older carers can contribute to the cohesion and stability of affected families and households and avoid their dissolution. Hence, the framework could be used to analyse whether policies and programmes address older carers' needs in a manner that supports caregiving activities, and enables the carers to provide

shelter, food, clothes, health care and education for affected household members, and sustains their own physical and mental health and well-being.

In addition, the framework could be used to draw input and comment from a broad range of stakeholders as a consultative document. Consultation may be carried out by NPOs representing older persons, who could use the framework to lobby the government. The older person representative NPOs could present the framework to the government at a provincial level, and to other stakeholders for collective action by all the role players to support older carers. Employment of the framework for these purposes could serve moreover to support all vulnerable older persons and their families, and not only those affected directly by the disease. Indeed, if new policies and programmes target only older persons affected by HIV and AIDS, problems such as stigma and discrimination faced by older carers' family and household could be exacerbated, since they and their family members might be isolated and harassed by community members owing to perceived government preferential treatment. Responses to the effects of the epidemic must thus target affected persons in all age groups and affected families in an integrated and comprehensive way (see UN, 2004a).

A policy framework based on the evidence presented in this dissertation is outlined below (see Figure 6.1). The framework has nine key desired outcomes, each with a basis for action, policy recommendations and potential indicators. The indicators suggested to measure government and civil society responses are tentative, and are intended for wide discussion and reformulation with role players at the district level. Proposals shown in Figure 6.1 are elaborated below.

The nine desired outcomes shown in the framework (Figure 6.1), together with the bases for action, policy recommendations and potential indicators are discussed separately for each outcome. The framework is directed at national, provincial and district levels, to be elaborated in a proposed action plan later in this chapter.

Figure 6.1: Policy framework for the support of older carers at district level

	Desired outcome	Basis for action	Policy recommendations	Potential indicator(s)
1	Strengthened capacity of older carers to care for infected and affected persons, and to protect themselves against HIV infection	Carers need access to information and resources to enable and equip them to care for PLWHA and OVC, and to protect themselves from infection	• Review (and reform, where appropriate) current policy and programme intervention on HIV and AIDS, to ensure older carers' inclusion and make provision to address their specific needs; • Provide carers with information, counselling support and life skills training to empower them and enhance their caregiving;	• Number of age appropriate information materials developed and distributed to educate older persons on HIV and AIDS; • Number of district health service points with dedicated staff to counsel and support older persons on HIV and AIDS;
2	Improved access for caregivers to essential services, including health care, water and sanitation.	Older carers may experience difficulty in accessing health service points and lack modern amenities in their dwelling.	• Ensure that basic health and nutrition services (e.g. vitamin fortified mealie meal) are available to older carers; • Assess older carers' dwelling infrastructure, and access to safe water and sanitation to facilitate caregiving; • Strengthen district planning and programmes by involving older persons or their representative organisations in the process.	• Number of older person headed household benefiting from government nutrition support programmes within a district especially rural communities; • Proportion of older persons' households with piped water and a flush toilet; • Number of district management teams with older persons or their representative organisation, per district.
3	Involvement of older carers or their NPOs in policy development (e.g. social grants policy)	The roles and contributions of older carers (e.g. caring and nurturing) must be recognised and supported by government, to enhance the capacity and caregiving carers	• Review and reformulate policy and programmes to ensure inclusivity and non-discrimination against older carers; • Encourage affected households to access social grants for which household members may be eligible; • Ensure that government departmental budgets provide for programmes to support older carers' households;	• Percent older persons or their representative NPOs participating in policy formulation processes; • Number of AIDS-disabled PLWHA receiving a disability grant per year; • Number of government departments budgeting for older persons' needs;

Cont./

Figure 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
			• Ensure that policies and programmes to support PLWHA promote family cohesion and solidarity, and encourage and enable orphaned children to remain with family; • Ensure that government departmental policies mainstream older persons' needs in general.	• Percent older persons' households receiving full municipal services per year.
4	Co-ordination of activities to support older carers at the district level	The numbers of poor and older persons with a commensurate demand for services are increasing	• Build the capacity of district level officials to become actively involved in policy development aimed at addressing the epidemic at a community level; • Ensure that district services reach vulnerable households; • Establish co-ordinating mechanisms at district level to ensure the exchange of information and collaborative efforts; • Strengthen district efforts to support sustainable and accountable responses to the epidemic; • Build strong working partnerships between district management and NPOs working with older carers.	• Proportion of district managers trained in policy development and implementation; • Number of districts with a fully functioning co-ordinating body at the end of each year; • Number of districts with a working partnership between district management and NPOs representing older persons per year.
5	Avoidance of ageism, stigma and discrimination	Concerted efforts are needed to address prejudice against older persons, and problems of HIV/AIDS stigma and discrimination against their households, through awareness campaigns that involve community leaders and convey key messages to different sections of the community.	• Encourage community leaders to talk openly about HIV and AIDS and their impact on older persons; • Encourage the identification of affected older person households and help to mobilise community responses;	• Number of workshops, public meetings and campaigns organised by community leaders to address issues of HIV/AIDS stigma and discrimination per year; • Proportion of affected older persons household identified and assisted through community efforts

Cont./

Fig 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
			• Destigmatise HIV and AIDS within families by targeting information campaigns and providing counselling to all family members.	
6	Engagement and dialogue with traditional healers on HIV and AIDS and older carers	Traditional healers live and work in the communities that are poor and most affected by HIV and AIDS	• Involve traditional healers in the mainstream public health approach in managing the epidemic; • Capacitate traditional healers through dialogue and educate them on the causation and spread of the disease; • Encourage traditional healers to help to counter myths, and promote responsible attitudes and behaviour towards older people and the epidemic.	• Number of traditional healers engaged in dialogue and educated on HIV and AIDS by government at district level; • Number of traditional healers educated in VCT counselling per district per year; • Number of HIV and AIDS clients referred by traditional healers to a district health service point.
7	Identification of older carers' need for adequate shelter and assistance with home improvement	Affected households accommodate a number of vulnerable family members. Physical space and the home environment are often inadequate to accommodate all household members	• Expedite delivery of affordable housing to indigent and affected families. Improve older carers' access to credit and housing loans; • Assist affected households with home improvement (room extensions, indoor water and sanitation, etc.)	• Percent of affordable, sufficiently spacious houses occupied by older caregivers per district per year; • Percent of older persons accessing micro credit and/or credit and housing loans per year.

Cont./

Figure 6.1 (continued)

	Desired outcome	Basis for action	Policy recommendations	Potential Indicator(s)
8	Promotion of age-friendly district health service points.	Older carers have multiple chronic health problems, and the strain of caregiving engender additional health problems	• Establish age-friendly health service points at the district level; • Train health providers at the district level on the relationship of age related health conditions and HIV and AIDS; • Improve referral systems for older clients, to enable them to conserve resources.	• Number of health service points with age friendly environments; • Proportion of health service points with effective referral and appointment systems for older persons per district; • Number of clinics with dedicated services for older persons per district health facility per month.
9	Raised awareness and increase advocacy for community mobilisation to create supportive environments for older carers.	The impact of HIV and AIDS on older carers, their families and communities cannot be addressed by any single sector. A multisectoral (i.e. public, private, traditional and/or community) approach is required	• Link HIV and AIDS prevention activities and care and support for PLWHA with support for older carers; • Encourage and support local initiatives that promote community and family solidarity, to withstand the direct and indirect impact of the disease on households; • Disseminate successful experiences and lessons learned in raising awareness on the plight of older carers. • Use of mass media (e.g. TV, radio, pamphlets and billboards) and interpersonal communications strategies which are culture based and targeted to the intended audience.	• Number of joint public gatherings and awareness campaigns designed to highlight the plight of older carers per year; • Number of materials produced and distributed on successful best practices to help raise awareness about older persons' plight per district. • Number of TV and radio programmes providing information on HIV and AIDS directed at and inclusive of older persons • Number of billboards and educational materials displayed in public spaces.

6.5.1 Strengthen older carers' capacity to care for infected and affected persons, and to protect themselves against HIV and opportunistic infections

The first desired outcome in the framework calls for the capacitation of older carers to carry out their caregiving responsibilities optimally and with the least strain on themselves, and to protect themselves from HIV infection and opportunistic diseases contracted through caregiving.

Basis for action

Evidence shows that older persons affected by HIV and AIDS need to be supported on multiple levels. First and foremost, they need to have access to information and resources on how to care for a PLWHA, and how to protect themselves from HIV infection and contain the spread of the disease. Crucial resources required in this regard include protective materials, psychological or emotional counselling, and social grants (grants for which household members may be eligible). However, older carers should not be viewed as passive recipients of resources made available to them, but as active participants and stakeholders in the planning and implementation of appropriate programmes. Such action on their part, and such recognition of their contributions on the part of other stakeholders, will enhance the carers' self-esteem, and ability to cope and contribute. Thus, older carers can become full partners in the fight against HIV and AIDS, and in the management of the effects of the epidemic.

Policy recommendations

- Government policy makers should review current policy and programme intervention on HIV and AIDS, to establish the extent to which the policies and programmes are inclusive of older carers, and provide support to address the carers' specific needs.
- Government should provide information, counselling, support and life skills training for older carers to empower them and enhance their caregiving. Joint efforts between the government and NPOs working to mitigate the effects of the disease in communities should provide age-group appropriate information and counselling services for older persons.
- Older carers' level knowledge on the sexual transmission of HIV should be complemented with the provision of additional information on the non-sexual transmission of HIV to older carers.

- The government should provide essential supplies to older carers for their universal protection. (latex gloves, plastic aprons, disposable napkins and sanitary containers, etc.).

Indicators

- The number of age appropriate information materials developed and distributed to educate older persons on HIV and AIDS. This indicator is designed to measure equity in terms of HIV and AIDS education and information distribution between the different population age groups. As HIV and AIDS is the country's most important Public Health problem, it is crucial that all sections of the population have equal access to recent scientific information, in a popularised format, on the disease. An indicator of equity can be measurement of the development of and access to information packages on HIV and AIDS by older persons. Information needed to formulate this indicator could be retrieved from reports of VCT centres and other health service points at district level. The indicator could be calculated according to *ratio of share of HIV and AIDS materials dedicated to older persons to share of total materials of HIV and AIDS information distributed.*
- The number of district health service points with dedicated staff to counsel, test and support older persons on HIV. This indicator also measures equity in health service accessibility for older persons. The indicator could be measured by *counting the number of health districts service points with dedicated staff to counsel and support older persons on HIV and AIDS.*
- The proportion of older carers with piped water and a flush toilet inside their dwelling. This indicator measures accessibility to local government services. The indicator could be calculated by *counting the number of older persons' dwellings in a district with piped water and an inside toilet compared to the total number of dwellings with similar facilities per district.* The data to calculate the indicator may be retrieved from district municipal records or monthly reports.

6.5.2 Improve access for caregivers to essential services

Many older carers lack basic services such as piped water and flush toilets, especially in rural areas. A lack of such facilities makes caregiving activities even more difficult for them.

Basis for action

Several older carers have difficulty in accessing health service points and providing a nutritious diet for their dependents, and lack piped water and flush sanitation in their

dwelling. Inaccessibility of health care services, or a lack of basic health infrastructure makes caregiving even more difficult for older carers and contributes to the strain and stress they experience. An inability to provide adequate nutrition for a PLWHA may result in more rapid deterioration of the PLWHA's condition, since the body needs proper nutrition to rebuild itself and to enable treatment to work effectively. Children (OVC) need good nutrition to thrive and perform well at school. The Declaration of Commitment of the UN Special Session on HIV/AIDS calls for increased access of vulnerable children to essential services and parity. As a signatory to the declaration, the South African government thus has an obligation to provide equitable services to households with vulnerable children, such as those affected by the disease. The provision of medications, food and nutrition education through home-based care and support programmes can benefit both caregivers and their dependents, and help to sustain the carers' contributions. The accessibility of social grants for which household members may be eligible must be improved, and the means test reviewed and/or disregarded where it denies a vulnerable household access to grants. Unemployed older carers who neither benefit from a social pension should be given rebates on utilities and residential tax relief. However, the old age grant was not designed to cope with the effects of disease such HIV and AIDS, but to cater solely for the basic needs of the beneficiary. Moreover, the data from this survey suggest that the amount of the grant is insufficient, and hence the recommendations in this regard.

Policy recommendations

- More humanitarian policy is needed to ensure that basic health care and nutrition services are available to older carers and their household. In rural areas, government agriculture departments could assist affected households with soil tilling equipment and seeds, to enable the carers and able-bodied household members to work their fields or gardens and grow fruit and vegetables for household consumption.
- Municipal officials charged with the provision of houses to needy persons in communities should assess older carers' dwellings, and assist where home improvements are required, such as room extensions, and the installation of piped water, indoor sanitation and improved ventilation.
- Joint action between NPOs, religious bodies and the government is needed to strengthen district planning efforts through an identification of bodies or individuals sympathetic and

working towards the well-being of older persons, who in turn may be involved in planning and implementation activities, to benefit older carer headed households.

Indicators

The percentage of health service points with health professionals trained in geriatric care. This indicator measures access to health services at the district level in relation to older persons' health care needs. "Geriatric care" is defined here broadly to refer to comprehensive and quality care to older persons. Such care refers to all that happens in older patients' encounters with the health system, including staff attitudes, assistive devices provided, the availability of drugs, and so on. The indicator could be measured by *calculating the number of health professionals with training in geriatric care divided by the total number of health professionals with other qualifications for primary health care services delivery at district level.* However, it has been argued that training on its own does not translate into implementation (Charlton et al., 2009). Data to calculate the indicator may be sourced in human resource records at the health service point. The structure(s) that should be responsible for such incentives and training could be the Department of Health's Public Health directorate under the sub-directorate chronic disease management, disability and geriatric care collaborating with the Departments of Education and Social Development's older persons' programme in conjunction with medical schools.

- The number of health service points with age-friendly environments, including accessible walkways and entrances for the convenience of older clients, per district. This indicator measures the physical accessibility of buildings to older persons. It may be calculated by *counting service points with low pavement, and unobstructed and smooth walkways for easy access for older persons*.
- The percentage of older carers living within X km from a health service point that operates 24 hours a day. This indicator measures the accessibility of health services to older persons. Access refers here to a lack of physical or economic barriers to care services, such as distance and inability to pay for health care. The indicator could be measured by *calculating the proportion of older persons living within X km (10 km radius as per WHO recommendation) from a public health service facility*. Data to populate this indicator could be obtained through a small survey on the health care needs of older persons in a particular district.

6.5.3 Involve older carers in the development of HIV and AIDS policy

Older persons should participate in matters concerning their development and become involved in efforts to fight and manage HIV and AIDS. Older persons should be viewed moreover as contributors to such efforts and not simply as older persons and hence a burden to society.

Basis for action

Older persons' roles and contributions to the care management of the epidemic must be recognised and supported, so that their caregiving capacity may be enhanced, and they are enabled to continue these roles and sustain their contributions. Such a tenet is in accordance with the UN's Madrid Plan (UN, 2002a). The plan outlines older persons' expectations, within the context of a society's economic needs, and calls for their enablement to participate in the economic, political, social and cultural life of their community. It provides specifically for the recognition and support of older persons' contribution to the fight against the epidemic. Moreover, the plan provides for concrete actions to be carried out by various stakeholders to realise its objectives.

Policy recommendations

- Government departments need to review and reformulate policy, and their strategic plan and programmes, to ensure that older persons, older carers in particular, are neither excluded nor discriminated against, especially in the areas of health, HIV and AIDS education and information, and housing.
- Affected households should be encouraged to access other social grants for which they are eligible, such as the child support grant, a foster care grant and a care dependency grant. In addition, the disability grant is available to eligible AIDS afflicted household members. Older carers should be helped to access grants, through assistance with gathering required documentation, and overcoming bureaucratic barriers and delays.
- Government departmental budgets should ensure they provide for programmes to support older carers' households, such as the provision of nutritious food for the PLWHA and OVC, waiving of school fees, monetary help with other school expenses, and so on. Government policies and programmes that support PLWHA should aim to strengthen family cohesion and solidarity, by providing means and support to keep orphaned children within a family environment and in their community.

- Government departmental policies should take into consideration older persons' needs in general, such as age friendly public spaces, public transport and other services, to ensure the well-being and independence of older persons.

Indicators

- The number of older person representative organisations that participate in relevant policy formulation processes each year. The indicator assesses the process of policy development and seeks to establish how inclusive the process is of key role players in the community. This indicator could be calculated by *the number of older person NPOs participating in policy formulation by the total number of other role players participating in policy development each year*.
- The number of PLWHA receiving a disability grant each year. This indicator measures accessibility of government support services to persons in an advanced stage of AIDS related illness. This indicator could be calculated by *counting the number of eligible PLWHA receiving a disability grant per district each year*. The data to calculate this indicator may be accessed from the Social Development department's quarterly or annual reports.
- The number of government departments allocating budget for older persons' needs. This indicator relates to financial planning by different government departments to address older persons' needs, at both national and provincial levels. The indicator may be calculated by *totalling government department budgetary allocations for older persons, divided by the total number of government departments at provincial level.*
- The number of older carers who pay school fees per annum. This indicator measures accessibility of government information (i.e. exemption of older primary carers from paying school fees in public schools) to older persons who are primary carers to grandchildren in school. The indicator could be calculated by *counting the number of older carers who pay school fees divided by the total number of parents who pay school fees per annum per district*. Data to calculate this indicator could be accessed from education departments' annual reports.

6.5.4 Co-ordinate activities to support older carers at the district level

The co-ordination of various activities to support older carers at the district level is fundamental to a mobilisation of their energy, and the contributions of various stakeholders, and the channelling of resources to households in need of support.

Basis for action

As more people become infected with the HI virus and AIDS related mortality increases, district governing bodies experience decreases in labour productivity, an increased demand for services, lower user capacity to pay for services, greater household vulnerability and increased numbers of vulnerable clients (older persons, OVC and PLWHA). District management needs to be supported by provincial and national government to be able to deal with such effects of the epidemic. Since districts are the government bodies closest to affected communities, they are in a unique position to identify vulnerable households, and to co-ordinate responses designed to mitigate the effects of the disease and implement prevention strategies. Clearly, district governing bodies cannot continue with "business as usual" in light of the effects of the AIDS epidemic (World Bank, 2003). Thus, new approaches are called for, on the part of district managers, which may include inviting and engaging other role players in the district regarding policy and programme development and implementation to support older carers and their households.

Policy recommendations

- National government needs to provide training in policy development and implementation for district personnel, to enable them to identify and put older persons' needs on policy agendas.
- Non-profit organisations working with affected carers should educate district officials on the plight and vulnerabilities of older carers and their household as a result of the disease, for them to gain understanding and to elicit their support for older carers' needs.
- District managers should ensure that district services reach vulnerable households, through consultation with NPOs, community based organisations and religious bodies that work with older carers.
- Provincial government should establish co-ordinating mechanisms between role players (NPOs, religious bodies, the private sector, the mass media etc) at the district level to facilitate an exchange of information (of services available to older persons) and collaborative efforts, to prevent duplication of efforts in the support of carers.

Indicators

- The proportion of district managers trained in policy development and implementation. This indicator measures the extent to which managers at district level are capacitated to drive and participate meaningfully in policy development and implementation processes. The indicator could be calculated by *determining the number of district managers trained in policy development compared to the total number of managers from both national and provincial levels trained per year.* Such information may be sourced from district managers' monthly or quarterly reports on staff capacity development.
- The percentage of older person households receiving full municipal services per year. A service accessibility measure, this indicator measures the extent to which older carer households have access to municipal services such as a safe water supply. The indicator may be calculated according to *the number of older person households receiving full municipal services by the total number of households receiving the services per year.* Data to calculate the indicator may be sourced from municipal records.
- The proportion of health districts with a working partnership between district management and NPOs representing older persons per year. This indicator measures the percentage of health districts with a working partnership and could be calculated by *determining the number of meetings and/or workshops held between NPOs representing older persons and district management to address older persons' needs compared to the total number of meetings the district management held with other role players per year*. The information may be obtained from district monthly or quarterly reports.

6.5.5 Avoid ageism, stigma and discrimination

The problems of ageism, stigma and discrimination faced by older carers in their communities, and to an extent in public institutions, are a cause for concern, and call for concerted efforts by all concerned to address and overcome them.

Basis for action

Awareness campaigns are needed to target community leaders who can convey key messages to diverse groups of people. Leaders may include district managers, representatives of community newspapers, religious leaders, sports personalities, youth leaders, community based organisation managers and others. Research findings could be presented in inclusive

community meetings and/or workshops, to educate and encourage community leaders to understand problems of ageism, stigma and discrimination with which older carers must contend. Such campaigns may help to obviate discrimination on all levels. Older persons may be invited to relate first-hand experience of discrimination against them in their community, health service points and other public institutions.

Policy recommendations

- Community leaders such as religious persons and youth leaders should talk openly about HIV and AIDS and on behalf of affected older persons, in order to bring their plight to the public's attention and to generate broad support.
- Non-profit organisations, religious bodies and other relevant community structures should help to identify, but not single out, older person households made vulnerable by the disease, and help to mobilise community response to support such households.
- Intervention programmes developed jointly by the government and NPOs should ensure that vulnerable older person headed households affected by the disease are not singled out, but that services are directed to all residents of a community rendered vulnerable by the disease. Community organisations working against HIV and AIDS should promote de-stigmatisation of the disease within communities by targeting information campaigns to, and providing counselling for, all family members.
- The number of workshops, public meetings and campaigns organised by community leaders through their NPOs to address issues of HIV and AIDS stigma and discrimination per year. This is an output indicator, and may be calculated by *measuring the volume of activities or actions taken by government or NPOs to realise a set target.* Information upon which to calculate the indicator may be extracted from NPO records or annual reports.
- The proportion of affected older person households identified and assisted to access government services through community efforts. This indicator measures access, and may be calculated by *counting the number of affected older persons' household to the total number of affected houses in general assisted by NPOs per district per month.* Data to populate the indicator may be obtained from NPO monthly or quarterly reports.
- The number of public institutions with dedicated advice and complaints offices for older persons. This is an age friendly outcome indicator, and may be populated *by*

counting the number of public institutions with dedicated age friendly offices per district.

6.5.6 Engage in dialogue with traditional healers/practitioners on HIV and AIDS and older carers

An estimated 200 000 traditional practitioners (of all categories) operate in South Africa and work parallel to the mainstream Public Health sector. The government is currently engaged in dialogue with these practitioners and is developing mechanisms to monitor their work.

Basis for action

Traditional healers practise in communities where poverty, HIV and AIDS co-exist. The role they play in the fight against the epidemic has been at variance with the mainstream approach, as was noted in the case studies. The practitioners seemingly do not share an orthodox understanding of the disease. Some argue, for example, that they can cure the disease through the use of traditional preparations. In the process, however, they charge clients, among whom are older persons, exorbitant fees for treatments; older clients invariably have scant resources which they deplete in this way, in desperation, in search of a cure. Traditional healers need to be educated about the vulnerability of older clients and the limitations of their healing powers. It is essential therefore that they be included in the mainstream Public Health approach to the management of the disease, to prevent confusion about their ability to heal, or indeed cure AIDS among vulnerable sections of the population. Traditional healers are familiar with their community's culture (the belief system, traditional practices, spiritual inclinations, and so on), and therefore potentially constitute a valuable resource to counsel older clients on HIV and to promote adherence to prescribed orthodox treatment regimens. Moreover, the practitioners need to be educated to refer HIV positive clients to Public Health service points for diagnosis and treatment.

Policy recommendations

- Involve traditional healers in the mainstream Public Health approach to the management of the epidemic. Avoid contradiction between information provided in Public Health messages on HIV and that provided by some traditional healers, by engaging the practitioners in dialogue.

- Capacitate traditional healers through dialogue and educate them on the causation and spread of the disease. Inform them that HIV is dissimilar to other sexually transmitted infections which they commonly manage in their communities, and is therefore incurable. Encourage them to not give false hope to desperate and vulnerable affected persons such as older carers about their ability to cure the disease.
- Help traditional healers to counter myths about the disease, and to promote responsible attitudes and behaviour towards the epidemic and avoidance of infection. Encourage them to promote HIV testing and the use of condoms, and lifestyle behaviour change as a main way to prevent the spread of HIV – rather than merely sell herbal preparations to vulnerable clients.

Indicators

- The number of traditional healers educated on HIV and AIDS by the government at the district level. This input indicator may be calculated by *counting the number of practitioners educated on HIV and AIDS per district*. Data for this indicator may be obtained from district health information systems or clinic records on community outreach programmes that focus on training of community organisations on HIV and AIDS.
- The number of traditional healers educated in VCT counselling per district per year. This is an input indicator, and could be calculated by *counting the number of traditional healers trained as VCT counsellors per district.* Data may be obtained from VCT service points.
- The number of HIV and AIDS clients referred by traditional healers to district health service points. This is a systems indicator, and measures the effectiveness of traditional healers' referrals to Public Health service points. The indicator may be calculated by *counting number of referrals made by traditional healers to health service points in relation to HIV and AIDS within districts per month.* Data to populate this indicator may be obtained from health clinic referral records.

6.5.7 Identify and assist with older carers with their need for adequate shelter

Older carers' stated need for adequate shelter featured prominently in outcomes of the survey and case studies in this dissertation, and warrants urgent attention from the government.

Basis for action

It is accepted that the government is unable to address all infrastructural development needs overnight, but it remains responsible for addressing housing needs. It equally remains a key role player and leader in responses to the effects of the epidemic. Young children rendered vulnerable or orphaned by the epidemic often move into the home of their grandparents, but the dwelling is often sorely inadequate and overcrowded. The government needs to set legal and policy mechanisms in place to ensure that national and international resources are mobilised to address the shelter needs of affected older carer households and vulnerable children urgently. NPOs as critical role players should assist the government to do so by identifying affected older carers, who should be given preferential consideration in the delivery of affordable and adequate housing, or at least whose dwelling should benefit from home improvements.

Policy recommendations

- Provincial government should give directives to high ranking officials, who with the assistance of caregiver NPOs should draw up a plan of action to speed up housing delivery for older carers' households.
- National advocacy NPOs need to strengthen efforts to increase older persons' access to credit and housing loans, especially those trying to cope with effects of the epidemic.
- Older carers are not only at risk of infection with the HI virus, but are exposed to opportunistic infections such as pulmonary tuberculosis. The provision of more spacious and better ventilated houses will help to reduce the spread of contagious opportunistic infections in this sub-population. Indoor piped water and flush toilets are crucial for optimal hygiene and facilitating caregiving.

Indicators

- The percentage of affordable and sufficiently spacious houses allocated to older caregivers per district per year. This indicator is an equity indicator, and measures accessibility of affordable decent housing provided by the government to older caregivers compared to other groups in the community at the district level per year. The indicator may be calculated by *counting the number of affordable houses allocated to older carers in a district by the total number of affordable houses allocated per year in*

a district. Information to populate the indicator may be obtained from the district housing department's records.

- The percentage of older persons accessing credit and/or housing loans per year. This is a service access indicator, and measures accessibility of credit and home loans to older persons. The indicator may be calculated by *counting the number of credit and housing loans made available to older carers proportionately compared to the total number of credit and housing loans provided by banks per year*. The information may be accessed through banks' monthly or quarterly reports.

6.5.8 Promote age-friendly district health service points

A recent worldwide trend in health service provision, introduced by the World Health Organization, is the promotion of age-friendly health district services to meet the health care needs of older persons equitably, especially those living in isolated poorly serviced rural areas.

Basis for action

While the government makes special provision for health care services to specific population age groups, such as the youth, children and expectant mothers, at the district level, it provides no dedicated geriatrics services for older clients which are desirable. Older persons have specific health care needs, especially relating to chronic ailments, and have physical and cognitive impairments. Older carers' health is seriously compromised through the strain of caregiving. National and provincial government thus needs to plan, in consultation with NPOs and district health managers, to provide dedicated health care services to older clients, with specific consideration given to the chronic health conditions and vulnerabilities of older carers. Such needs embrace basic health care, nutritional services, welfare services, dental care, eye care and other essential services. The services should be delivered in age-friendly environments. District level managers should commit themselves to policies that sustain older carers' capacity to support themselves and others in their household.

Policy recommendations

- National and provincial government should promote age-friendly health service points at the district level. Features of such environments may include accessible seating; signage in large lettering and local languages indicating facilities such as the pharmacy,

dressing room, social worker and dentist; and separate appointment and referral systems for older clients.

- Provincial government should discourage age discrimination in vital services such as primary health care services voluntary counselling and testing (VCT), and education on HIV and AIDS at community health centres.
- National and provincial government should train health care providers at the district level in the management and prevention of age related physical health conditions, such as hypertension and arthritis, and mental illnesses such as depression, stress and insomnia.
- Provincial and district government should improve the availability and supply of medicines to treat health conditions commonly found in older persons at district level health service points.
- Older persons' health support groups need to be established at district health service points, to provide co-counselling with treatment use and adherence, especially in the case of chronic conditions.

Indicators

- The number of health service points with age-friendly environments per district. This indicator measures accessibility of health service points for older persons within districts. The indicator could be measured by *counting all health service points that meet the above criteria within the district.* Data to populate the indicator may be obtained from health service point infrastructure design reports and by physical inspection of the facilities.
- The proportion of health service points with effective referral and appointment systems for older persons per district. This indicator measures systems performance, and assesses whether the referral and appointment systems benefit older patients insofar as services at the receiving health facility are readily available, and clients/patients are not turned away owing to unavailability of services, incorrect appointment times, and incorrect or inappropriate referrals. To populate this indicator one may have *to interview health service providers, but who tend to exaggerate the availability of services, or how adequate the referral or appointment system is.* Hence, one may need to randomly select recently referred older clients to the health service point and interview them.

- The number of older persons serviced at dedicated clinics per district health facility per month. This is a quality measurement indicator, and measures health service performance *vis-à-vis* provision for the health needs of older clients. Information gathered to populate the indicator may be used for district health service reform, and may be obtained from monthly or quarterly health service points reports.

6.5.9 Raise awareness and advocate for community mobilisation to create a supportive environment for older carers

Awareness raising through mass meetings, and the dissemination of literature and mass media broadcasts, especially over the radio, have a potential to draw the attention of a wide and diverse audience to the plight and support needs of older carers. Such strategies should be pursued aggressively to garner support for older carers. In this regard, social marketing which combines traditional marketing approaches, new technology, as well as integrated action and planning for social change is recommended (Kotler & Roberto, 1989).

Basis for action

The impact of HIV and AIDS on older carers, their family and community is multifacetted and cannot be addressed by any single sector (public, private or community) alone. HIV and AIDS related situations therefore call for awareness raising among the public at all levels. Advocacy based on empirical evidence on the havoc caused by the epidemic on the lives of older persons and their households is needed urgently, so that appropriate responses may be designed and implemented, and supportive environments created for the carers and their households. Social marketing has been used in several SSA countries (e.g. the Democratic Republic of the Congo, Kenya, Lesotho and Zimbabwe) to retard the tide of the epidemic (PSI, 2005) with some success. Previous communication campaigns by Soul City and LoveLife were shown to influence behaviour change in relation to HIV and AIDS, fight stigma and generate support for PLWHA in South Africa.

Policy recommendations

- Government and NPOs at provincial and local levels should link HIV and AIDS prevention, care and support activities for PLWHA and OVC with responses to the support needs of older carers, to ensure that all affected household members are targeted in intervention.

- Government and NPOs should develop appropriate social marketing tools to address the effect of the epidemic on affected older persons.
- NPOs and the private sector should encourage and support local initiatives, such as support groups that promote community and family solidarity, to withstand the direct and indirect impact of the disease on households.
- The government could provide physical space in under-used government property for support groups to meet and discuss issues relating to HIV and AIDS. Government at national and provincial levels should make use of its vast resources (personnel; infrastructure, funds, etc.) to disseminate examples of successful experiences and lessons learned in raising awareness on the plight of older carers.
- Social marketing using mass media (e.g. TV, radio, pamphlets and billboards) and interpersonal communications strategies which are culture based and targeted at intended audiences.

Indicators

- The number of joint public gatherings or awareness campaigns held between government, the private sector and NPOs designed to highlight and address the plight of older carers per year. This is an output indicator measuring collaborative efforts between the different role players at the district level. The indicator may be calculated by *counting the total number of the joint gatherings per year*. Information to calculate the indicator may be obtained from the NPO and/or local government annual reports.
- The number of information documents (booklets; pamphlets; flyers, posters, etc.) distributed by the government on successful efforts to raise awareness about older persons' plight issued per district per year. This indicator is an input indicator and measures efforts to highlight the plight of older persons at a community level. The indicator may be calculated by *counting the number of documents distributed per year*. Information may be obtained from NPO records or annual report and or government annual report.
- Number of television and radio programmes providing information on HIV and AIDS directed at or inclusive of older persons.
- Number of billboards and educational materials displayed in public spaces.

The indicators suggested in the policy framework do not cover the full spectrum of those that could be used conceivably to measure the performance of different stakeholders in planning and provision to meet older carers' support needs. Some indicators may be used to measure more than one activity outlined in the framework. However, the use of the proposed indicators will rely on role players to gather and record activities throughout the year, so that performance and trends of service point activities can be measured. A plan of action to guide the use of the framework is proposed below.

6.6 PLAN OF ACTION TO GUIDE EMPLOYMENT OF THE POLICY FRAMEWORK

The policy framework outlined above provides a basis for the review and reform of relevant policy, to meet the support needs of older carers, and offers policy recommendations and indicators to measure implementation outcomes of new policy and programmes. Government policy makers may scrutinise the policy framework, and after consultation with relevant role players, may take decisions to:

- Review existing relevant policy and programmes to ascertain the gaps in supporting older carers and their dependents (i.e. PLWHA and OVC).
- Engage with stakeholders in the formation of a working group to design best strategies to address, or alleviate the carers' plight.
- Re-assess the situations of older carers and their households, primarily a responsibility for NPOs, to determine support needed, and the scope and effectiveness of existing responses.
- Consider how the support needs of older carers could be mainstreamed in existing policies and programmes, or whether there is a need for new dedicated policy and programmes to support the carers and their households.
- Design a comprehensive strategy on how to address the gaps in government policy and programmes and older carers' needs and how such a strategy could or should involve older carers or their representative organisations.
- Identify resources required by various role players: budgets, time, staff, volunteers, infrastructure, etc., to implement policy actions and achieve desired outcomes. A

realistic assessment of role players' capacity will assist them to focus their energy and resources on what is achievable within a specific time frame.

NPOs whose input will be potentially crucial in the various processes include Age-in-Action, Grandmothers Against Poverty and AIDS (GAPA), Neighbourhood Old Age Homes (NOAH), the South African Older Persons' Forum (SAOPF), the South African Red Cross Society and the Muthande Society for the Aged (MUSA). Another NPO is Catholic Welfare and Development (CWD), whose focus is on community development in general, and deals with issues of women empowerment and provides services to the vulnerable and marginalised sections of society, among whom are the poor, homeless and unemployed within the Western Cape Province. CWD works to empower the youth, women, refugees, the elderly and those living with HIV and AIDS. Other NPOs that may be involved are the Nelson Mandela Children's Fund and the Desmond Bishop Tutu HIV Foundation, both of which empathise with older persons.

Functions and tasks of various stakeholders, or role players may include:

- The appointment of a working group by the government, in consultation with stakeholders, to identify a role player(s) to drive one or more desired outcomes proposed in the framework.
- The compilation of examples of successful, relevant community responses to the epidemic, such as home based care programmes (e.g. Red Cross Society), community health and rehabilitation workers (e.g. Zibonele Community Health Project), by NPOs that serve older clients as best practices for replication by relevant role players.
- Consultation with the private sector being on roles it might play and contributions it could make. Commercial banks could be approached to revise discriminatory home loan and credit policies that exclude older persons who wish to improve the condition of their dwelling. Older carers may want to borrow money from a bank to buy a new and bigger house for their family.
- Consortia of government departments at provincial level and other stakeholders could mobilise and ensure optimal utilisation of resources (financial, human, infrastructural and knowledge related) to achieve desired outcomes. Ways in which role players may be involved in resource mobilisation could include i) the government facilitating and co-ordinating other role players' activities, and various government departments providing budgetary allocations to support the realisation of the plan; ii) non-profit

organisations offering dedicated support programmes for older persons, such as income generation skills development and food gardening programmes; and iii) religious bodies offering emotional counselling, and providing physical space for support group meetings, training, and skills development activities (e.g. income generation; budgeting and networking).

Supplementary information needed to support the development and implementation of new policies and programmes informed by the policy framework is considered below.

6.7 INFORMATION NEEDED TO INFORM APPROPRIATE POLICY AND PROGRAMME DEVELOPMENT AND IMPLEMENTATION

The plan of action provided is intended to guide the role players specifically in the employment of the framework. However, settings are varied and situations are fluid, and policies, strategies and programmes that emanate from consultation and indeed adoption of the framework may need to be informed by supplementary and context specific information. Such information may need to cover areas and be elicited through actions such as follow:

- A determination of prevalence rates of HIV in older persons and older carers' risk of infection in various provinces and locations.
- An exploration of opportunities and information needed to establish working relationships between district management and older persons' NPOs, with a view to joint action to support older carers, such as information and education on HIV and AIDS.
- A determination of the nutritional needs of older carers, PLWHA and OVC, as a basis for their inclusion in food support programmes.

The policy framework is mainly shaped by the empirical evidence garnered from the respondents. A challenge that lies ahead is how policy and strategic plans may be directed to and taken up at district levels, where the study population is located, and is largely ignorant of available government services. A lack of food, one of the greatest support needs identified, is critical in the majority of this population's households. In addition, the availability of food is crucial in the management of HIV and AIDS.

6.8 EVALUATION OF THE APPROPRIATENESS AND FEASIBILITY OF THE POLICY FRAMEWORK

The policy framework developed in this chapter is designed to assist role players in supporting older carers affected by the HIV and AIDS epidemic in South Africa. The framework highlights the central role that government must play at all levels in facilitating and co-ordinating the activities of different role players at the district level in this regard. A strength of the framework may lie in its inclusive approach, which aims to involve all role players – government departments, non-profit organisations, religious bodies, traditional healers, the private sector, academic institutions, the media and older carers themselves – in the review, and reformulation, or development of new policies and programmes to address older carers' needs specifically, but in an integrated way. The framework aims to build bridges within and across formal and informal sectors of society, and within and outside of government departments. A strategy plan that may be developed by stakeholders, informed by the framework, could serve to improve stakeholders' access to resources and provide for a more efficient use of resources and greater acceptability of policies and programmes. A strength of the framework lies similarly in its being based on empirical evidence, as against theoretical argumentation, and its argument for a bottom-up approach to public policy development.

A limitation of the framework may be its reliance on a political willingness of the government to adopt the framework and implement its recommendations. The framework will compete for the government's attention with the needs of other more vocal interest groups in society, such as trade unions, gender groups and youth groups, all of which are better organised than older person groups. The adoption, or employment of the framework as a guiding tool will therefore depend on the willingness of politicians and policy makers to recognise the extent of older carers' plight and the urgency of their needs.

The proposed policy framework recommendations are not a panacea for all problems of service inaccessibility experienced by older caregivers. The recommendations are made rather with a view to strengthening or enhancing what infrastructure and services are already in place. It is not disputed that the South African government already does a great deal for indigent older citizens through the grant system (see Moller & Sotshongaye, 1996; Sagner & Mtati, 1999**).** However, insufficient or poor accessibility of services for older persons,

because of barriers such as a lack of affordable transport to access health care, prevails in non-urban areas especially. Research indicates moreover that entry points to health services points must be barrier-free (WHO, 2004; Fitzpatrick et al., 2004). Physical and service delivery barriers need to be removed to enable older persons with temporary or permanent functional limitations to access needed care, and to maintain health and independence. Age-friendly public health facilities at the district level can help to sensitise and educate health providers about the specific needs of this section of the population.

CHAPTER SEVEN: CONCLUSIONS, EVALUATION AND RECOMMENDATIONS

7.1 INTRODUCTION

In this chapter, conclusions of the dissertation and empirical study are drawn, the hypotheses are confirmed, the study and dissertation are evaluated, and recommendations are made for future policy and research in the subject area. Specifically, and broadly rather than sequentially, I reflect on the results of the empirical study; discuss findings of the study and the dissertation; evaluate how the mixed-methods approach enabled an identification of concerns and difficulties experienced by older persons in the course of caregiving to PLWHA and OVC; and make recommendations pertaining to a role for primary health care (PHC) to address older persons' health needs at the district level, as well as to areas in which further research is needed. The recommendations are made for the consideration of all stakeholders involved in the fight against HIV and AIDS, and who are concerned about or tasked with providing for the health and well-being of older persons in the SSA sub-region and in South Africa specifically. Among relevant stakeholders are government departments, NPOs, CBOs, FBOs, traditional healers and the private sector.

7.2 CONCLUSIONS

Conclusions drawn pertain to findings of the study and the dissertation as a whole. I emphasise a need, based on the evidence presented in this dissertation, for older carers to be supported formally: not only as increasingly dependent and vulnerable people, but also to enable them to help themselves – thus, strengthening their capacity to help those for whom they care.

7.2.1 Filling gaps in knowledge

The findings of the empirical study supported prior evidence on several issues relating to caregiving by older persons in the sub-region; the findings also identified a number of new issues about which little is thus far known. Evidence from the empirical study showed, for example, that not only older women are primary carers to PLWHA, but older men as well. Second, the study established how the epidemic in South Africa affects family structures and

family relationships between older members and younger members. Third, evidence was gleaned on the extent to which the effects of the epidemic overwhelm the adaptive capacity of affected households, specifically with respect to household finances and food security. In addition, the dissertation has contributed to gerontological knowledge broadly – and to the development of African gerontology specifically. The dissertation has made out a case for protecting the health of older persons in order to prolong their life and sustain their well-being, and benefit the people for whom they care. The findings affirm the extent and multiplicity of the problems that the disease creates for older carers and their households in the sub-region – and contribute to filling emerging gaps in knowledge.

The study has contributed to knowledge on changing patterns in traditional kin support systems. Although stronger historically in non-urban settings than in urban settings, the structures appear to be weakening under the strain of the epidemics – in both settings. A progressive loss of support capacity of affected households is what prompted numerous caregivers in the study to identify a need for financial support. Indeed, the study has brought most of the determining factors that define the nature of the double burden of caring for an older chronically ill person(s) caring for young children. Interventions such as government policies and programmes to support the carers should thus take into account the levels at which the interventions need to be implemented optimally: i.e. at the levels older carers, their households and their community as a whole.

7.2.2 Filling a gap in Public Health knowledge and practice

The dissertation has established, through the review of the international and regional literature and evidence yielded in the empirical study, that older persons play a valuable role and contribute to primary health care delivery within their household. Where they care for PLWHA and OVC, they are a vital link in the care continuum between a hospital, clinics, the community and a household, even though they may have no formal training in caregiving. Indeed, the majority of older carers simply assume this role by default, because of the non-availability, or a lack of willingness of other family members to discharge such a responsibility.

The dissertation has identified a growing future concern, namely that older persons may be at similar risk of infection as younger people through unprotected heterosexual sex. The number

of older persons in South Africa (Shisana et al., 2006) and the SSA sub-region (HelpAge International, 2008a) infected with the virus is increasing rapidly. Older persons are therefore equally in need of public health interventions such as AIDS information, education, testing and counselling, and other preventive and treatment measures, as persons in other age groups.

The fact that the empirical study found a reluctance on the part of older carers to take their sick child(ren) and/or grandchildren to state health service points is a reflection of their perception that health providers, or the health system, are unable to respond to the evolving health care needs of affected communities. A lack of age-friendly health service facilities at the district level, and thus poor access by and unsatisfactory services for older clients, is a matter in need of redress by the Department of Health.

The study also contributes to knowledge by highlighting the role that older carers play in their community and family as development agents, through their nurturing and educating of young children in their care. The additional contributions made to human and other development in turn contribute to the achievement of Millennium Development Goals (MDGs) in affected countries.

Older persons are in many senses *de facto* health care providers to their households. Their involvement in health care delivery should thus be encouraged and utilised at the district level, provided that they are capacitated with the necessary skills, knowledge and support. Specifically, older persons have a role to play in delivering primary health care relating to HIV and AIDS prevention, care and treatment support and monitoring. Thus, they should be consulted and included in public health intervention programmes, such as HIV counselling and monitoring of treatment use by PLWHA: as peer educators and distributors of condoms, among other roles. They could also play a role in monitoring how older persons are serviced at PHC service points at the district level, such as whether they benefit from the cost exemption policy for older persons.

Involving older persons as community members in the delivery of health services – a central principle of primary health care – will create a sense of ownership among them, of the programmes at their local health clinic. Older persons as a group could serve as a permanent source of support to health service delivery at the district level, although their membership will change intermittently through attrition. They would nonetheless need to be given

periodic support and opportunities for training and for the exchange of ideas and experiences with clinic health staff. They could be an invaluable resource, especially in resource constrained environments, such as rural areas and shanty towns with a dire shortage of health personnel.

7.2.3 Filling a gap in research methodology

Studies of older persons and HIV and AIDS in the sub-region have only been conducted in the last decade or two, and as the review of the relevant literature has shown, have been fairly similar in the small scale and the single setting or research site of the studies. The research methods employed in the majority of these studies have not been particularly innovative, and may have failed, by and large, to give a full picture and understanding of the study population's situation and needs. None of the studies as far as could be established has employed a mixed-methods approach. A contribution of the present study and dissertation therefore lies in the use of a mixed-methods approach and triangulation of data from multiple data sets to understand the multi-dimensionality and complexity of the effects of HIV and AIDS on older carers.

Use of this approach enabled an exploration of the study problem from different populations and perspectives, and on different levels. First, analysis of the survey data provided an understanding of the magnitude of the problem in the delimited settings in the three targeted South African provinces, and of differences in the effects of the disease in urban areas and non-urban areas. Second, analysis of the study data provided an understanding of how the carers perceive their situation, and how in their opinion it should be addressed by the government and other relevant stakeholders. Third, analysis of the key informant interviews data provided the views and understanding of non-profit organisations' managers, government officials on the plight of older persons managing HIV and AIDS and how policy address or does not address their support needs. Finally, triangulation of the data and findings from three data sets provided a comprehensive analysis of the three data sets, where areas of concurrence and divergence were identified. The latter approach also served to show the lack of understanding by government officials of the older carers' burden and support needs.

Hence the dissertation has demonstrated the value of using a mixed-methods approach and a case is made out for its use in future studies in other settings, including comparative studies.

7.3 EVALUATION OF THE DISSERTATION

7.3.1 Contribution to knowledge and society

The dissertation has contributed to knowledge in the subject area through its review and synthesis of a large body of international, regional and national literature, instruments and policies, as well as the evidence generated in the empirical study. A key outcome of this review and study is the documentation of empirical evidence on the effects of the epidemic on older persons, as caregivers to sick and dying children and how they cope with limited support from NPOs and a lack of formal support. The study also showed that some older males, albeit a small number in this sample, are primary carers, contrary to traditionally and culturally accepted roles for males in this society. Another contribution is the identification of gaps in the extant literature, and policy instruments and documents reviewed, and the specific attempts made in the dissertation to fill some of these gaps. Overall, it has been argued that older carers' or their representative bodies' issues and concerns have thus far largely been overlooked in all policy development and intervention. Highlighting this gap may contribute to future policy formulation and reform. Thus, the dissertation and its outcomes can help to put older carers and their support needs on centre stage, especially regarding issues relating to their capacity – and need for support – to be able to render care optimally and cope, and to sustain their own health.

7.3.2 Contribution to Public Health Care

The greater part of the literature on health provision indicates that state health systems in the SSA sub-region do not cater adequately, for the health care needs of older persons, especially at the district level. The dissertation has made a strong case for, opportunities to deliver appropriate and optimal health care to this population – and thus support older carers at the district level. The policy framework proposed in Chapter 6 in this regard identifies a set of potential health indicators to guide and measure successful implementation of appropriate, inclusive PHC programmes – in both urban areas and non-urban areas. The study also highlighted an apparent disinclination of older persons in the Eastern Cape Province to access health care services, compared to counterparts in the other two provinces, possibly because of poor health care infrastructure and barriers to health care in the Eastern Cape, but which finding needs further investigation. The finding nevertheless indicates a need for improved health care services for older clients in that province, and indeed countrywide.

In addition, the dissertation has highlighted the desirability of older persons' or their representative organisations' direct involvement in the monitoring and evaluation of the implementation of policy provisions: both those that affect them and those relating to HIV and AIDS in general. Practical steps that may be taken to involve older persons in such activities could include development of a standardised protocol for their inclusion and participation in such policy processes. Such a practical tool may serve as a guide to senior district health managers on how to work with older persons or their representative organisations, and in which ways.

Identification of the health care needs and participation of older persons as primary carers in communities and households contributes to an understanding of the needs (e.g. information, education and training, and skills development) of these lay primary health care providers. Indeed, recognition that older persons render home care in their community may be a valuable entry point for public health care programmes to support older carers. The policy framework proposed in Chapter 6 can serve as a tool to be consulted by various role players at the district level to identify and act on issues relating to the needs of older carers and older persons in general: for example, improve their accessibility to health services, and provide them with safe water and suitable sanitation.

The dissertation promotes the principles of primary health care, such as PHC as a collaborative effort between all relevant role players, which can help to build links with other support services and facilitate timely referrals of older persons and/or their charges to other levels of care within a continuum of health care.

Obstacles remain in the development and implementation of programmes to meet older persons' and older carers' health care and support needs. These obstacles include a scarcity of resources – financial, infrastructural and human, and a negative mindset towards older clients on the part of health providers towards older persons. Ultimately, older persons – or older health care clients – must not be perceived as a liability, or a drain on health resources, but as contributors to the well-being of others in their community and households (Ferreira et al., 2007). Indeed, their contributions, capacity and wealth of experience need to be harnessed and sustained, and applied and utilised for the benefit of all.

7.3.3 Application of theory

The development and employment of an analytical and explanatory theoretical framework for the study, drawing on social exchange theory and feminist theory, enabled an application of theory in an investigation of caregiving by older persons in response to HIV and AIDS in a developing country, in this case South Africa. The theoretical applications highlighted the disproportionate caregiving burden on older women, and their comparative gender related disadvantage in several domains, as well as the dynamics of intergenerational caregiving behaviour, and which actors benefit (or may not benefit) at particular stages, and how and why.

7.3.4 Application of research methodology

The empirical study employed a relatively large survey sample which covered three provinces and was recruited in both urban settings and non-urban settings. The research design provided for the use of both quantitative and qualitative research data collection methods, with an aim to generate information towards an understanding and elucidation of the demands of caregiving and the challenges for older carers. The mixed-methods approach, which incorporated triangulation of the data from the three data sets, employed helped to fill a methodological gap left in the majority of earlier studies in this problem area, elaborated in the dissertation. The application of a mixed-methods approach enabled the researcher, methodologically and substantively, moreover to meet the study's objectives: Specifically, i) a determination of the nature and burden of care on older caregivers in households affected by HIV and AIDS; ii) an identification of the financial, physical, social, emotional and health care needs of older caregivers, as well as factors facilitating and hindering caregiving, such as a lack of financial resources; iii) an assessment of how various role players at the district level can work together to support older person households affected by HIV and AIDS; and iv) the establishment of extensive evidence for policy makers and programme planners, to inform them in the design and implementation of appropriate policies, strategies and programmes for the benefit of older carers.

However, while the study and dissertation conceivably achieved the objectives that were set, areas in need of further research were identified in the course of the work, which are outlined in sub-section 7.5.3 below.

7.4 RECOMMENDATIONS

The three hundred and five older persons who participated in the study constitute only a "tip of the iceberg" in the picture that they provided of the immense suffering and vulnerability of older carers in South Africa and other sub-regional countries. Numerous recommendations to improve their situation and reduce their burden were made within the policy framework proposed and outlined in Chapter 6. Additional recommendations, of a broader or more specific nature, are made below.

7.4.1 Towards improving older carers' quality of life

It is crucial that older carers' situations are improved, through support from the government and other role players. The dissertation has demonstrated that interventions to achieve this goal may be best effected through public health agencies at the district level. Enhanced quality of life for older carers can serve indirectly to improve the health and well-being of those in their care.

Specifically, older carers' quality of life may be enhanced by improving their access to essential services, such as health care, safe water and the removal of bureaucratic barriers – for example, where they need to obtain legal documents. Although the majority of the carers surveyed received an old age grant, the amount of the benefit was shown to be insufficient to provide for the needs of multiple household members. Thus, the government might investigate the feasibility of providing care grants to older persons who care for PLWHA and vulnerable children. Besides, helping them to meet the needs of affected and vulnerable children and grandchildren, such a policy, would be in accordance with the Millennium Declaration of Commitment on HIV and AIDS. Such measures, taken together, would go a long way towards improving the carers' quality of life, especially through enhanced physical health, and emotional and psychosocial well-being, and improved ability to cope, while off-setting additional financial burdens they experience.

At the same time it is important that older persons themselves are enabled to become actively involved in addressing socio-economic, development and health issues that affect their lives. Although the older carers' attitudes towards their involvement in health care delivery were not investigated as such, studies conducted elsewhere, e.g. in Asia and the Pacific (see

Masulit, 1998; World Bank, 2006; HAI, 2006a), have shown that older persons are eager to participate in this function. Older persons in the Philippines, for example, were trained as "community gerontologists" to work closely with doctors, dentists and nurses at Primary Health Care facilities (Masulit, 1998). They were later able to perform basic medical checks, keep records and refer complicated cases to health professionals. In numerous other affected countries, such as Thailand and countries in Africa, older persons are already involved, albeit without formal training, in health caregiving, as evidenced through care of their sick children (i.e. PLWHA).

7.4.2 Towards formulating and implementing appropriate Primary Health Care responses

The survey showed that older carers suffer from poor health generally, which is manifested in chronic conditions such as hypertension, arthritis and depression. Thus, older carers need better access to health care services in the public sector, at the district (primary care) level, that can manage disease conditions common in older persons, and in older carers effectively and acceptably to the clients. Such measures should include the establishment of age-friendly health service points at the district level, and the discouragement of age discrimination in vital services such as counselling and reproductive health care. This study has shown that some health personnel at the district level have little understanding of how to relate to older clients and to provide health services that meet their needs.

Additional measures taken should include improved referral and appointment systems for older clients, to enable them to conserve limited time and financial resources. Older clients should moreover not be charged for primary health services. The policy provision exempting beneficiaries of an old age grant from paying a fee for primary health care is frequently disregarded. Health care providers at the district level need specific training in the treatment of age related health conditions, as well as HIV and AIDS in older persons, the symptoms of which, such as muscle wasting and confusion, are often ascribed to ageing and neglected.

While overall levels of awareness and knowledge of key aspects of HIV and AIDS were found to be satisfactory in the sample of older caregivers, credit for such knowledge levels should probably be given to NPOs. However, persistent myths and misconceptions about the cause and management of the disease were still found among some caregivers. The salutary work of NPOs in this regard should therefore be complemented and reinforced through

dedicated campaigns drawing on relevant messages from respected older leaders such as Mr Mandela, Mrs Sisulu and Bishop Tutu. The messages could be conveyed through the mass media (radio in particular), in the languages of the targeted audiences. Such campaigns may help to dispel myths identified in the study. It is important that all aspects of the epidemic, including voluntary counselling and testing, nutrition, treatment, home-based care and human rights, are emphasised in the campaigns.

7.4.3 Identification of further research needed

Further research in the problem area is indicated. In particular, age-disaggregated data need to be collected on the needs and roles of older people, to inform the design of appropriate HIV and AIDS interventions inclusive of older persons and their needs. The impact of poverty on HIV and AIDS related caregiving, as it affects older carers, needs to be linked to national poverty monitoring and evaluation systems by the government, so that an understanding may be achieved of how the two phenomena reinforce one another in affected older-person households. A better understanding is needed moreover of the health seeking behaviour of affected older persons, and to what extent AIDS-related caregiving is a causative factor of their ailments.

The ways in which traditional healers may be engaged and their resources harnessed in the fight against AIDS need to be better understood: specifically, how the healers may be encouraged to work with older carers in appropriate ways (see Peltzer et al., 2005). Evidence based information is needed to guide the design of educational materials on HIV and AIDS, which should be age and gender sensitive, and incorporate the views and experiences of older persons. Finally, forward looking research is needed to determine what the ramifications may be of greater HIV prevalence – and care and support needs – in future older cohorts.

Additional consideration may still need to be given to the development and employment of research methods that will look at the long-term implications of the present effects of the epidemic on communities and households – hence, longitudinal studies. Moreover, more studies are needed on the role of older men as caregivers in AIDS affected households, and *their* perceptions of government intervention(s) to alleviate the burden of caregiving. Importantly, more extensive baseline data are needed to measure progress towards resolution of older carers' problems.

7.5 CONCLUDING REMARKS

It was the researcher's intention that gaps in knowledge identified in the statement of the problem, and the identification of a need for empirical evidence in the problem area, should be filled to a large extent by the evidence generated in the study. The study has contributed in a large measure to filling such gaps, but, more information is still needed on the effects of the disease on older persons in different settings in all of South Africa's nine provinces. In particular, older men whose participation in caregiving receive far less attention compared to their female counterparts with respect to what they contribute, how they are affected and what specific support needs they require given that caregiving historically has been women activity. Crucially, all sections of South African society – and indeed SSA societies – need to participate in efforts to address the support needs of older caregivers, guided by the principles of Primary Health Care (WHO, 1978) and the Universal Declaration of Human Rights (UN, 1948) – such as inter-sectoral collaboration, community involvement, and treatment with equality and dignity. Thus may affected and vulnerable older caregivers and their households be identified more easily, and interventions to support them and meet these needs implemented.

The findings of the study have implications for policy. It was established that present government policy intervention, such as the HIV and AIDS strategic plan and programmes such as voluntary counselling and testing, PMTCT, condom distribution and education information campaigns, lag in addressing older carers' support needs. Moreover, social protection, in the form of old age grants, is inadequate. The existing grants should not have to meet the multiple expenses that older carers must shoulder because of effects of the epidemic and a lack of other formal support. A review of the formulae used to calculate the nature and amount of grants, and whom they are targeted at and for what purposes, is strongly indicated. Improved or expanded social protection for older carers would constitute an important step towards sub-regional governments' fulfilling regional and national commitments to human rights goals for older persons. Similarly, the South African government should review its housing policy for the indigent section of society, inclusive of older persons, as a matter of urgency, and revise the formula for, and fast track the process of allocating houses in which the housing needs of poverty-stricken older caregivers are prioritised.

The undermining of older persons' human rights in the limited information and education on HIV and AIDS available to the older population runs contrary to South Africa's constitutional provisions – in this case, the right to information and education. The government's national campaign on adult literacy should therefore address the education and information needs on HIV and AIDS for older persons inclusively and specifically, applying proven methods and principles of adult literacy programmes, such as respect for learner knowledge and experiences.

In addition, government departments, especially at provincial level, need to work more closely with one another regarding HIV and AIDS and its effects on older persons. The dissertation has shown that provincial health department personnel tend to view the problems spawned by the epidemic for older persons as being a responsibility of other department(s), not that of their department. Certainly, the evidence shows that problems created by the disease are cross-cutting, and need inter-sectoral responses and action. The dissertation has tried to indicate what leadership public health care agencies can take and roles they could play in this regard at the district level.

Indeed, Chapter 6 in the dissertation highlighted the importance of collaborative action between the relevant role players. The policy framework proposed outlines how stakeholders could work together, by each identifying an area of activity where its focus and strengths lies, with the government at the district level playing an overall facilitating and co-ordinating role. Indicators have been proposed to assist stakeholders to measure the realisation of recommendations towards improving older carers' support needs, well-being and quality of life. In addition, the framework identifies barriers to action on the part of the government, such as a general ignorance of older carers' support needs, and how these persons may be targeted in interventions. A key implication of the dissertation and its findings, however, is that a realisation of the policy recommendations will require appropriate budgetary arrangements, and planning to ensure effective implementation and long-term financing of the activities to support older carers.

REFERENCES

Abdool-Karim, Q. 1995. The HIV/AIDS epidemic. *South African Health Review*. Durban: Health Systems Trust.

Aber, L., & Richter, L. 2005. *Family and school-based interventions to improve psychosocial outcomes of children affected by HIV/AIDS*. Unpublished paper. Durban: Child, Youth and Family Development, Human Sciences Research Council.

Abel, T., & Werner, M. 2003. HIV risk behaviour of older persons. *European Journal of Public Health*. 13: 350.

Aboderin, I. 2007. Development and ageing policy in sub-Saharan Africa: Approaches for research and advocacy. *Global Ageing*. 4(3): 7–22.

Aboderin, I., & Ferreira, M. 2008. *Linking ageing to development agendas in sub-Saharan Africa*: *Challenges and approaches*. World Demographic Association Discussion Paper Series. Available: www.wdassociation.org [2008, March 26].

Abt Associates, and Health Economics and HIVAIDS Research Division (HEARD). 1999. HIV/AIDS and health. *AIDS Toolkits*. Durban: Abt Associates, University of Natal.

Abuja Declaration. 2001. The declaration on HIV/AIDS, tuberculosis and other related infectious diseases. Special Summit devoted specifically to address The Challenges of HIV/AIDS, Tuberculosis and Other Related Infectious Diseases. Abuja.

Actuarial Society of South Africa (ASSA). 2004. ASSA AIDS and demographic models: ASSA2002. Available: www.assa.org.za [2006, June 17].

Adamchak, D.J., Wilson, O.A., Nyanguru, A., & Hampson, J. 1991. Elderly support and Intergenerational Transfer in Zimbabwe: An analysis of Gender, Marital status, and Place of residence. *The Gerontologist*, 41(4): 505-513.

Adler, W.H., Bender, B.S., & Nagel, J.E. 1998. Immune function and AIDS in the older patient. *Infection Medicine*. 15(12): 842–846.

Adler, W.H., & Nagel, J.E. 1994. Acquired immunodeficiency syndrome in the elderly. *Drugs Aging*. 4(5): 410–416.

Adult Abuse Review. 2002. World Health Organization release report on adult abuse. Available: http://www.wordbridges.net/elderabuse/AAR/Vol1Issue2/WHOreport.html. [2008, March 29].

AED-USAID. 2003. *Multisectoral response to HIV/AIDS: a compendium of promising practices in Africa*. USAID-PVO Steering Committee on Multisectoral Approaches to HIV/AIDS. New York: USAID Bureau for Africa, Office of Sustainable Development.

Africa Strategic Research Corporation. 1999. *Abuse of the elderly in South Africa*. Pretoria: Human Sciences Research Council.

African (Banjul) Charter on Human and Peoples' Rights. 1986. (OAU Doc. CAB/LEG/67/3) Available: *www1.umn.edu/humanrts/instree/z1afchar.htm*
[2007, June 27].

African Development Bank. 2005-2009. *Country strategy paper*. Manzini, Swaziland: ADB.

African Development Forum (AFD). 2000. *The African consensus and plan of action: Leadership to overcome HIV/AIDS*. Addis Ababa, Ethiopia, December 3–7.

African Union (AU)/ HelpAge International (HAI). 2003. *AU Policy Framework and Plan of Action on Ageing*. Nairobi: HAI Africa Regional Development Centre.

Aged Support Society of Malawi (ASSOM). 2005. *Report on the research study on the aged persons in Malawi: Towards understanding their situation and challenges.* Manzini: Department of Population Studies, University of Swaziland.

Aggleton, P. 2000. *Comparative analysis: Research studies from India and Uganda. HIV and AIDS related stigma, discrimination and denial.* Geneva: UNAIDS.

AIDS Law Project n.d. *Women, HIV and AIDS: HIV/AIDS current law and policy*. Johannesburg: Centre for Applied Legal Studies, Johannesburg: University of the Witwatersrand.

AIDS Policy Law. 1997. Biting was a homicide. 12(9): 12. Available: www.medsite.com. [2006, September 13].

Akinsola, H. A. 2001. Fostering hope in people living with AIDS in Africa: The role of the Primary Health Care worker**.** *Australian Journal of Rural Health*. 9: 158–165.

Akintola, O. 2004. *A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal.

Akukwe, F.N. 1992. *Senior citizens: A policy dilemma.* Onitsha, Nigeria: Veritas.

Albert, S.M., & Cattell, M.G. 1994. *Old age in global perspective*. New York: G.K. Hall.

Allander, J.A., & Spradley, B.W. 2005. *Community Health Nursing: Promoting and protecting the public's health.* 6th ed. London: Lippincott Williams & Wilkins.

Alonzo, A.A., & Reynolds, N.R. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3): 303–315.

Anderson, S., & Kaleeba, N. 1994. AIDS care in the family. *World AIDS Day News*, 3:1. Available: www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=A…
[2006, November 8].

Ankrah, M.E. 1991. AIDS and the social side of health. *Social Science & Medicine*. 32(9): 967–980.

Ankrah, M. E. 1993. The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care*. 5(1).

Anyango, O.M., Momanyi, K.J., & Muriuki, J. 1995. *Feelings and experiences of single HIV-positive women about their children*. Paper presented in the IXth International Conference on AIDS and STDs in Africa, Kampala, Uganda.

Appay, V., & Rowland-Jones, S.L. 2002. Premature ageing of the immune system: the cause of AIDS? *Trends in Immunology*. 23(12): 580-585.

Appleton, J. 2000. "At my age I should be sitting under that tree": The impact of AIDS on Tanzanian lakeshore communities. *Gender and Development.* 8(2): 1927.

Arhihenbuwa, C. 2003. *Health and culture: Beyond the Western paradigm*. London: Sage.

Arndt, C., & Lewis, J.D. 2000. The macro implications of HIV/AIDS in South Africa: a preliminary assessment. (Special submission.) *South African Journal of Economics*.

Aubel, J. 2001. Strengthening grandmother networks to improve community nutrition. *Gender and Development.* 9(2): 30–35.

Aubel, J. 2005. *Grandmothers: A learning institution*. Washington, D.C.: Creative Associates and USAID.

Aubel, J., Sihalathavon, D., & Kopke, D. 1997. *Participatory health education project with grandmothers in Laos, Vietnam.* (unpublished).

Aubel, J., Toure'; I., & Diagne, M. 2004. Senegalese grandmothers promote improved maternal and child nutrition practices: The guardians of tradition are not averse to change. *Social Science & Medicine*, 59: 945–959.

Auvert, B., Taljaard, D., & Sobngwi-Tambekou, J. et al. 2005. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: The ANRS 1265 Trial. *Public Library of Science Medicine*. 2(11): 1-11.

AVERT. n.d. *Sexually transmitted diseases. Symptoms, treatment and facts*. West Sussex: AVERT. Available: www.avert.org/disclaimer.htm. [2005, November 10].

Ayiga, N., Ntozi, J. P.M., & Ahimbisibwe, F. E. et al. 1999. Causes, patterns differentials and consequences of AIDS mortality in Northern Uganda. *The Continuing African HIV/AIDS Epidemic.* 139–154.

Babbie, E. 1983. *The practice of social research*. Belmont, CA: Wadsworth.

Babbie, E. 1990. *Survey research methods.* 2nd ed. Belmont, CA: Wordsworth.

Babbie, E. 2001. *The practice of social research.* 9th ed. Wadsworth/Thomson Learning.

Bachmann, M.O., & Booysen, F.L. 2002. Health and economic impact of HIV/AIDS on South African households: A cohort study. *Journal of British Medicine and Public Health*. 3(14): 1–8.

Baggaley, R., Sixaxe, T., & Gaillard, P.2000. Involving men in MTCT intervention, October, submitted to *AIDS Care*.

Barrientos, A., & Lloyd-Sherlock, P. 2003. Non-contributory pensions and poverty prevention. A comparative study of Brazil and South Africa. Report. Manchester: IDPM and HelpAge International.

Barnett, T., & Blaikie, P. 1992. *AIDS in Africa*. London: McMillan.

Barnett, T., & Whiteside, A. 2002. *AIDS in the 21st Century: Disease and globalization: Critical perspectives on Southern Africa* 54. Ann Arbor, MI: State University Press.

Bartlett, G. 1997. Management of healthcare workers infected with HIV: The SHEA position paper. *The Hopkins HIV Report.* New York: John Hopkins University.

Bateman, C. 2001. Can KwaZulu-Natal hospitals cope with the HIV/AIDS human tide? *South African Medical Journal.* 91(5): 364–368.

Baum, A., & Nesselhof, S. 1998. Psychological research and the prevention, etiology, and the treatment of AIDS. *American Psychologist.* 43(11): 900-903.

Baum, F., & Sanders, D. 1995. Can health promotion and primary health care achieve health for all without a return to their more radical agenda. *Health Promotion International.* 10: 149-160**.**

Baumgarten, M., Hanley, J.A., Infante-Rivard, C. et al. 1994. Health of family members caring for elderly persons with dementia. *Annual International Medicine.* 120: 126-132.

Baydar, N., & Brooks-Gunn, J. 1994. The dynamics of child support and its consequences for children. In *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS. Research Report on Recommendations.* Cape Town*:* Children's Institute, University of Cape Town.

Baylies, C. 2002. HIV/AIDS and older women in Zambia: Concern for self, worry over daughters, towers of strength. *Third World Quarterly.* 23: 351–375.

Benatar, S. 1991. Medicine and health care in South Africa – five years later. *The New England Journal of Medicine.* 325: 30–36.

Benatar, S. 2004. Health care reform and the crisis of HIV and AIDS in South Africa. *New England Journal of Medicine.* 351: 1.

Bennell, P., Hyde, K., & Swainson, N. 2002. *The impact of the HIV/AIDS epidemic on the education sector in sub-Saharan Africa: A synthesis of findings and recommendations of three country studies.* Sussex: Department of Health, University of Sussex.

Beresford, B. 2002. Failing to deliver. The government is battling to provide a welfare safety net for families affected by HIV/AIDS. *Weekend Mail and Guardian*, October 11 p.8.

Bergin C., O'Reilly, M., Goha, J. et al. 2000. Incidence of sexually transmitted diseases amongst an elderly cohort attending a Genito-urinary medicine clinic. *Journal of the European Academy of Dermatology and Venereology*. 5(3): 218-221.

Berg, B.L. 2001. *Qualitative research methods for the social sciences* 4th ed. Boston: Allyn & Bacon.

Berman, H. J. 1987. Adult children and their parents: Irredeemable obligation and irreplaceable loss. *Gerontological Social Work with Families*, 10:21–34.

Besley, M.A. 2005. *AIDS and the family: Policy options for a crisis in family capital*. New York: Sage.

Birdsall, K., & Kelly, K. 2005. *Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey*. Johannesburg: Centre for AIDS Development, Research and Evaluation (CADRE),

Bittles, A.H. 1991. Biological aspects of human ageing. In *Psychiatry in the elderly*. Jacob, R., & C. Oppenheimer, Eds. Oxford: Oxford Medical Publications.

Blaikie, A. 1999. Ageing: old visions, new times? *Lancet*, 354: 4.

Blau, P.M. 1964. *Exchange and power in social life*. New York: Wiley.

Blenkner, M. 1965. Social work and family relationships in later life with some thoughts on filial maturity. In *Social structure and the family: Generational Relations.* Shanas, E., & G. F. Streib, Eds. Englewood Cliffs, NJ: Prentice Hall.

Blieszner, R., & Hamon, R. R. 1992. Filial responsibility: Attitudes, motivators, and behaviors. In *Gender, families and elder care.* Dwyer, J. W., & R. T. Coward, Eds. Newbury Park, CA: Sage.

Blinkhoff, P., Bukanga, E., & Syamalevwe, B. et al. 1999. Under the Mpundu tree: Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt, *Strategies for Hope Series*, 14 London: ActionAid.

BOLD. 2006. Grandmothers at the AIDS conference. The Toronto statement. *BOLD*. 17(1): 30–31.

Boneham, M.A., & Sixsmith, J.A. 2006. The voices of older women in a disadvantaged community: Issues of health and social capital. *Social Science & Medicine*. 62: 269–279.

Booysen, F. 2002. Financial responses of households in the Free State Province to HIV/AIDS-related morbidity and mortality. *South African Journal of Economics*. 70(7).

Booysen, F., & Van der Berg, S. 2005. The role of social grants in mitigating the socio-economic impact of HIV/AIDS in two Free State communities. *South African Journal of Economics*. 73: 546–563.

Bowling, A. 1997. *Research methods in health: Investigating health and health services*. Buckingham, PA: Open University Press.

Brabeck, M., Brown, L., & Espin, C. L. et al., 1997. Feminist theory and psychological practice. In *Shaping the future of feminist psychology: Education, research, and practice.* Worell, J., & N. Johnson, Eds. Washington, DC: American Psychological Association, pp.15-35.

Bradshaw, D., Nannan, N., & Laubscher, R. et al., 2000. *South African national burden of disease study: Estimates of provincial mortality. Eastern Cape Province*. Parow: South African Medical Research Council.

Bredenkamp, C. 1999. *Falling through the cracks? Income security and the South African social security system*. Unpublished Masters dissertation. Stellenbosch:
University of Stellenbosch.

Bromley, D.B. 1986. *The case-study method in Psychology and related disciplines.* Chichester: Wiley. 51, 56 & 372.

Browne, C. 1994. Feminist theory and social work: A vision for practice with older women. *Journal of Applied Social Sciences*, 18: 5–16.

Browne, C. 1995. A feminist lifespan perspective on aging. In *Feminist practice in the 21st Century*. N. Van Den Berg, Ed. Washington, D.C.: NASW Press.

Brown, J.R. 1996. *The I in science: Training to utilize subjectivity in research*. Oslo: Scandanavian University Press, Universiteitforget AS.

Browne, C. 1998. *Women, feminism, and aging*. New York, NY: Springer.

Bryman, A. 1989. *Research methods and organisation studies*. London: Unwin Hyman.

Bumagin, V.E., & Hirn, K.F. 2001. *Caregiving: A guide for those who give care and those who receive it*. New York: Springer.

Burns, N., & Grove, S.K. 2001. *The practice of nursing research – conduct critique and utilization*. 4th ed. Philadelphia: W.B. Saunders.

Buch, E., Mathambo, V., Ferrihno, P. et al. 2003. *Leakages in PMTCT care in a district hospital in KwaZulu-Natal, South Africa*. Durban: Health Systems Trust.

Burman, E. 1994. Interviewing. In *Qualitative methods in Psychology*. Banister, P.E., I. Burman, Parker, M. Taylor, & C. Tinal, Eds. Milton Keynes: Open University Press.

Burman, S. 1996. Intergenerational family care: legacy of the past, implications for the future. *Journal of Southern African Studies.* 22(4): 585–598.

Burton, L.M. 1992. Black grandparents rearing children of drug-addicted parents: Stressors, outcomes, and social service needs. *Gerontologist.* 12: 744–751.

Butt, A.A., Dascomb, K.K., De Salvo., K.B. et al. 2001. Human immunodeficiency virus infection in elderly patients. *South African Medical Journal.* 94(4): 397–400.

Calasanti, T. 1999. Feminism and gerontology: Not just for women. *Hallym International Journal of Aging* 1: 44–55.

Caldwell, M. 2001. *Prospects for the aged in the developing world*. Paper read in the UNPFA Symposium on the Aged, IUSSP conference, Salvador de Bahia.

Caliandro, G., & Hughes, C. 1998. The experience of being a grandmother who is the primary caregiver of her HIV positive child. *Nursing Research.* 47: 107–113.

Callaghy, T.M. 1993. The state as lame Leviathan: Patrimonial administrative state in Africa. In *The African state in transition*. Ergas, Z., Ed. New York: St.Martin's Press, 87-116.

Campbell, D.T. 1979. "Degrees of freedom" and the case study. In *Qualitative and quantitative methods in evaluation research*. Cook, T.D., & C.S. Reichardt, Eds. Beverly Hills, CA: Sage.

Cameron, E. 1993. Legal rights, human rights and AIDS: The first decade. Report from South Africa. *AIDS Analysis Africa*, 3: 3-4.

Canfield, J. 1997. *Philosophy of meaning, knowledge and value in the* 20th *century*. London: Routledge.

Carael, M., & Holmes, K. 2001. The multicentre study of factors determining the different prevalences of HIV in sub-Saharan Africa. *AIDS.* 15(4): 5-14.

Carballo, M., & Carael, M. 1988. Impact of AIDS on social organization. In *The global impact of AIDS.* Alan, R., & I. Fleming, Eds. New York: John Hopkins Bloomberg, 81-94.

Carroll, J.S., & Johnson, E.J. 1990. Decision research: A field guide. *Applied Social Research Methods Series*, 22. London: Sage.

Carvalho, S., & White, H. 1997. Combining the quantitative and qualitative approaches to poverty measurement and analysis: the practice and the potential. *World Bank Technical Paper* 366. Washington, D.C.: World Bank.

Case, A. 2001. *Does money protect health status? Evidence from South African pensions*. Princeton: Princeton University Press.

Case, A. 2004. Does money protect health status? Evidence from South African Pensions. In *Perspectives on the economics of Aging*. Wise, D., Ed. Chicago: University of Chicago Press.

Case, A., & Deaton, A. 1996. Large cash transfers to the elderly in South Africa. *The Economic Journal.* 108: 1330-1361.

Cassiem, S., & Streak, J. 2001. *Budgeting for child socio-economic rights: Government obligations and the child's rights to social security and education*. Cape Town: Idasa.

Centre for Development and Population Activities (CEDPA). 1975. *Faith community responses to HIV/AIDS. Integrated reproductive health and HIV/AIDS for NGOs, FBOs & CBOs. 2*. Washington, D.C.: USAID.

Center to Improve Care of the Dying (CEDA). n.d. *Faith community responses to HIV/AIDS. Integrating reproductive* h*ealth and HIV/AIDS for NGOs, FBOs & CBOs*. Training manual series. 1. Washington, D.C. Available: www.gwu.edu/u~cicd/tookit/caregive.htm. [2006, April, 04].

Centres for Disease Control (CDC). 2008. HIV/AIDS among persons aged 50 and older. *CDC HIV/AIDS fact*. Available: http://www.cdc.gov/hiv/topics/over50/resources/factsheets/pdf/over50.pdf. [2008, November 22].

Chaklader, H. 2004. *Baseline survey on older people*. Dhaka: Bangladesh Women's Health Coalition.

Challis, L., Fuller, S., Henwood, M. et al. 1994. Investigating policy co-ordination: issues and hypotheses. In *Public sector management: Theory, critique and practice*. McKevitt, D., & Lawton, Eds. London: Sage.

Charlton, K.E., Kawana, B., & Hendriks, M. 2009. An assessment of the effectiveness of growth monitoring and promotion practices in the Lusaka district of Zambia. *Nutrition*, 25(10): 1035–1049.

Chela, C.M. 1995. *Assessing the cost-effectiveness of home based care in Zambia*. Paper presented in the 2nd International Conference on Home and Community Care for Persons Living with HIV/AIDS, Montreal.

Child Health Policy Institute & The Children's Rights Project. 2000. *Policy and legislation framework. Children with disabilities and chronic illnesses: Their right to social security*. Paper presented in the National Workshop on Social Assistance for Children with Disabilities and Chronic Illnesses, Cape Town, May 15-16.

Children's Institute. 2002. *Social security benefits for children and families*: *Comment made to the Department of Social Development on the Report of the Committee of Inquiry into Comprehensive Social Security System*. Cape Town: Children's Institute, University of Cape Town.

Chima, R., Chima, I., & Azie, U. 2004. *Ageing and HIV/AIDS: Impact, responses and weak links*. Paper read in the African Conference on Ageing, Johannesburg, August 18-20**.**

Chimwaza, A., & Watkins, S. 2002. Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care*, 16(7): 795-807.

Chodorow, N.J. 1989, 1991. *Feminism and psychoanalytic theory*. New York: Yale University Pres.

Clair, J.M., Karp, D.A., & Yoels, W.C. 1993. *Experiencing the life cycle.* Springfield, IL: Thomas.

Clandinin, D.J., & Connelly, F.M. 2000. *Narrative inquiry; Experience and story in qualitative research.* San Francisco: Jossey-Bass.

Clapham, C. 1996. *Africa and the international system*: *The politics of survival*. Cambridge: Cambridge University Press.

Clark, R.E., & Drake, R.E. 1994. Expenditure of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal.* 30(2): 145-163.

Clark, S.J., Collison, M.A., & Kahn, K. 2005. Returning home to die circular labour migration and mortality in northeast South Africa. *Scandanavian Journal of Public Health* (under review).

Clausen, F., Sandberg, E., & Ingstad, B. et al. 2000. Morbidity and health care utilization among elderly people in Mmakgodi village, Botswana. *Journal of Epidemiology and Community Health*. 54(1): 58-63.

Cleveland, C.J. 2007. *The human development index: going beyond income*. New York: United Nations Development Programme. Available: www.eoearth.org/article/Botswana's_Human_Development _Index_for_2004>. [2008, January 29].

Cloud, G.C., Browne, R., Salooja, N. et al. 2003. Newly diagnosed HIV infection in an octogenarian: elderly are not "immune." *Age Ageing*. 32(3): 353-354.

Coll-Seck, A. 2001. *Access to treatment.* UNAIDS/UNDP Workshop, Harare, Zimbabwe, February 15.

Commission for Africa (CfA). 2005. *Our common interest*. Report of the Commission for Africa. London: Commission for Africa Secretariat.

Commission for Gender Equality (CGE). 2005. Submission to the South African Parliamentary National Assembly. Portfolio Committee on Social Development: Older Person's Bill. Cape Town.

Commission for Social Care Inspection (SCI). 2006. Institutional elder abuse. *Journal of Elder Abuse and Neglect*. 10: 43– 60.

Coopoo, S. 2000. *The women's budget series. Women and local government review,* 2000. Community Agency for Social Enquiry and Parliamentary Committee on the Quality of Life and Status of Women. Cape Town: IDASA.

Coovadia, H.M., & Coutsoudis, A. 2002. Problems and advances in reducing transmission of HIV-1 through breastfeeding in developing countries. *AIDScience*. 1(4): 1-13.

Cowgill, D.O. 1986. *Aging around the world*. Belmont, CA: Wadsworth.

Cowgill, D.O., & Holmes, L.D. 1972. *Aging and modernization*. New York: Appleton-Century-Crofts.

Creswell, J.W. 1994. *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Creswell, J.W. 1998. *Qualitative enquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Creswell, J.W. 2003. *Research design: Qualitative, quantitative and mixed methods approaches.* 2nd ed. London: Sage.

Critical Health Editorial Collective. 1988. AIDS in South Africa: progressive perspectives. *Critical Health*. 22.

Cumming, E., & Henry, W. 1961. *Growing old*. New York: Basic Books.

Curtis, M. 1996. *Marxism: The inner dialogue*. 2nd ed. London: Transaction.

Davids, A., Skinner, D., & Letlape, L. 2002. *Our children our future: From vision to innovative impact, community responses to orphans and vulnerable children*. Pretoria: Human Sciences Research Council.

Dorrington, R., Johnson, L., Bradshaw, D. et al. 2006. *The demographic impact of HIV/AIDS in South Africa: National and provincial indicators for* 2006. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

Dawson, D.A, Cynamon, M. & Fitti, J.E. 1987. AIDS knowledge and attitudes: Data from the national health interview survey. *Advance Data*. 146: 1-10.

Dayritt, M.M., Monzon O.T., & Bassaca-Sevilla, V. et al. 1987. Emerging patterns of HIV infection and control in the Phillipines. *Western Journal of Medicine*. 147(6): 723-725.

Dayton, J., & Ainsworth, M. 2002. *The elderly and AIDS: Coping strategies and health consequences in rural Tanzania*. Population Council Publication, No. 160. New York: Population Council.

Dean, K. 1986. Lay care illness. *Social Science & Medicine*. 22: 275-84.

De Gorgolas, M., Bello E., Garcia Vazquez, E. et al. 1999. In old age …AIDS. Is it worth to initiate antiretroviral treatment? Review of 37 patients more than 60 years of age. *Annals of Medicine International*. 16(6): 273-2766.

Deininger, K., Garcia, M., & Subbarao, K. 2001. *AIDS-induced shock as a systemic shock: Magnitude, impact and programmatic interventions in Africa*. Washington, D.C.: World Bank.

De Jong, J. 2003. *Making and impact in HIV/AIDS: NGO experiences of scaling up*. London: ITGD Publishing.

De Maeseneer, J., Willems, S., De Sutter, A. et al. n.d. Primary Health Care as a strategy for achieving equitable care: A literature review commissioned by the Health Systems Knowledge Network. Available: www.who.int/social_determinants/resources/csdh_media/primary_health_care_2007_en.pdf. [2008, November 29].

Denzin, N.K. 1989. *Interpretive biography*. Newbury Park, CA: Sage.

Denzin, N.K., & Lincoln, Y.S. 2003. Strategies of qualitative inquiry. 2nd ed. Thousand Oaks, CA: Sage.

Drew, R.S., Mgombane, G., & Nyaruwa, T. 1997. Estimating coverage of a community based home care programme. *Tropical Doctor*. 27: 210-214.

Department for International Development, UK. 2005. *Social transfers and chronic poverty: Emerging evidence and the challenge ahead*. London: DFID.

Devereux, S. 2002. Can social safety nets reduce chronic poverty. *Development Policy Review*. 20(5): 657-675.

Development Research and Training. n.d. Ugandan participatory poverty assessment process (UPPA). Kampala Ministry of Finance, Planning and Economic report. Uganda.

de Vos, A.S., & van Zyl, C.G. 1998. The grounded theory methodology. In *Research at grass roots. A primer for the caring professions*. A.S. de Vos, Ed. Pretoria: Van Schaik. 265-276.

Diof, W. 2000. Adult learning in a non-western context: The influence of culture in a Senegalese farming village. *Adult Education Quarterly*. 51(1): 32-44.

Disney, R. 2002. Africa in crisis. Hazards rise for prime-age adults. *Insights. Pension for life?* 42. Sussex: The University of Sussex.

Dlamini, N. 2005. *The main challenges in mainstreaming gender***.** Paper presented in the: 7th AIDS Impact Conference, Cape Town, October.

Doll-Yogerst, D. n.d. *The key informant approach*. Available: www. uwex.edu/ces/pdande/progdev/pdf/keyinform.pdf. [2005, December 18].

Dolbin-MacNab, M.L., & Targ, D.B. 2003. Grandparents raising their grandchildren: Guidelines for family life educators and other family professionals. In *Working with custodial grandparents*. B. Hayslip, & J.H. Patric, Eds. New York: Springer. 213-228.

Donabedian, A. 1980. *Explorations in quality assessment and monitoring.* Ann Arbor, MI: Information Management, Health Administration Press.

Drench, M.E., & Losee, R.H. 1996. Sexuality and sexual capacities of elderly people. *Rehabilitation Nursing*. 21(3): 18-23.

Drevenstedt, J. 1976. Perceptions of onsets of young adulthood, middle age, and old age. *Journal of Gerontology*. 31: 53-57.

Drinka, T.J., Smith, J.C., & Drinka, P.J. 1987. Correlates of depression and burden for informal caregivers of patients in a geriatrics referral clinic. *Journal of the American Geriatrics Society*. 35: 522-525.

Duflo, E. 2003. Grandmothers and granddaughters: Old age pensions and Intra-household Allocation in South Africa. *World Bank Economic Review*. 17: 1-25

Dugbatey, K. 1999. National health policies: sub-Saharan African case studies (1980-1990). *Social Science & Medicine*. 49(2): 223-240.

Du Guemy, J. 2001. *The elderly, HIV/AIDS and sustainable rural development*. Sustainable Development Department, Food and Agriculture Organization, United Nations (FAO). Available: www.fao.org/sd/2002/PE0101a_en.htm. [2005, March 22].

Dunkin, J.J., & Anderson-Hanley, C. 1998. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology*. 51(1): 53-60.

Ehrlich-Sachs, S., & Sachs, D. 2004. Africa's children orphaned by AIDS. *The Lancet*. 364: 1404.

Ekpeyong, S. 1995. The structural adjustment programme and the elderly in Nigeria. *International Journal of Ageing and Human Development*. 41(4): 267-279.

Eldemire-Shearer, D. 1999. Change, family life, coping strategies and seniors, *Aging and Development Report*, London: Help Age International. Available: www.helpage.org/Resources/Policyreports/main_content/1118337994-011/AgeingAfricaSummary.pdf *[2007, December 12]*.

Emerson, R.M. 1972. Exchange theory, part II: In *Exchange relations and networks*. Berger, J., Zeldich, M., & Anderson, Eds. Boston: Houghton-Mifflin, pp. 58-87.

Emerson, R.M. 1976. Social exchange theory. *Annual Review of Sociology*, 2: 335-362.

Engelhardt, J., Brubaker, T., & Lutzer, V. 1998. Older caregivers of adults with mental retardation: Service utilization. *Mental Retardation*. 26: 191-195.

Esu-Williams, E. 2003. Involving youth in the care and support of people affected by HIV and AIDS. *Horizons Research Summary*. Washington, D.C.: Population Council.

Fatimi, Z., & Avan, I . 2002. Demographic, Socio-economic and Environmental determinants of utilization of antenatal care in rural setting of Sindh, Pakistan. *Journal of Pakistan Medical Association*. 52: 138-142.

Feldman, P. H., Nadash, P., & Gursen, M. 2001. Improving communication between researchers and policy makers in long-term care: Or, researchers are from Mars; policy makers from Venus**.** *The Gerontologist*. 41(3): 312.

Ferreira, M. 1997. South Africa's social pensions system: Who benefits and how? In *Ageing in changing societies: Africa preparing for the next millennium*: Ferreira, M., N. Apt, & A. Kirambi, Eds. London: Brook Green Print.

Ferreira; M. 1999. The generosity and universality of South Africa's social pension system, *the Courier*, 176: 55-56.

Ferreira, M. 2000. Growing old in the new South Africa. *Ageing International*. 25: 32-46.

Ferreira, M. 2004. Elder abuse in Africa: What policy and legal provisions are there to address the violence? *Journal of Elder Abuse & Neglect*, 16: 17-32.

Ferreira, M. 2006. HIV/AIDS and older people in sub-Saharan Africa: Towards a policy framework. In Age, ageism, and HIV and AIDS. J. Sykes & S.J. Aziz .Eds. Global Ageing. Canada: HelpAge International Press. 56-69).

Ferreira, M., & Charlton, K.E. 1996. Towards an integrated, community based social and health care programme for older residents of Mitchell's Plain: A study report. Cape Town: HSRC/UCT Centre for Gerontology.

Ferreira, M., Charlton, K.E., & Mosaval, Y. 1998. Retired farm workers, farm evictions and the "dop" system: An exploratory study in three towns in the Western Cape Province. Study report. Cape Town: HSRC/UCT Centre for Gerontology.

Ferreira, M., Gurland, B., Bloom, H. et al. 2007. Study to Understand and Foster the Functioning and Involvement of Contributive Elders (SUFFICE). Report on a pilot study towards a health intervention. Cape Town: University of Cape Town, Institute of Ageing in Africa.

Ferreira, M., Keikelame, J., & Mosaval, Y. 2001. Older women as carers to children and grandchildren affected by AIDS: a pilot intervention project. Cape Town: University of Cape Town, Institute of Ageing in Africa.

Ferreira, M., & Kowal, P. 2006. A minimum data set on ageing and older persons in sub-Saharan Africa. Process and outcome. *African Population Studies*, 21(1): 19-36.

Ferreira, M., & Kalula, S.Z. 2007. Ageing and human rights South Africa. In:. *Human rights in an ageing world: Perspectives from around the world*. Macleod, R., Ed. London: International Longevity Centre-United Kingdom. 7-10.

Ferreira, M., & Lindgren, P. 2008. Elder abuse and neglect in South Africa: a case of marginalization, disrespect, exploitation and violence. *Journal of Elder Abuse and Neglect.* 20(2): 91-107.

Ferreira, M. (monica.ferreira@uct.ac.za). 2008. [Personal communication, 15 November] to G. Petros (sabela.petros@uct.ac.za)

Ferreira, M., & Kalula, S. 2009. Ageing women and health: Emerging caregiving needs in sub-Saharan African countries. *BOLD*, 19(4): 2–12.

"Filthy" health clinic has become a gutter: Patients say they are treated with lack of respect. 2008. *Cape Argus,* November 19, 16.

Fink, A. 1995. *The survey handbook.* Thousand Oaks, CA: Sage.

Fisher, A.A., & Foreit, J.R. 2002. *Designing HIV/AIDS intervention studies: An operations research handbook.* New York: Population Council Inc.

Fitzpatrick, A., Power, N., & Cooper, L. et al., 2004. Barriers to health care access among the elderly and who perceives them. *American Journal of Public Health*, 94(10): 1788-1794.

Flick, U. 1998. *An introduction to qualitative research: Theory, method and applications.* London: Sage.

Forbes, A. 2000. Raising grass-roots demands for microbiocides in the USA. Global campaign for STI/HIV prevention alternatives for women. *Sexual Health Exchange*. 4: 12-13.

Ford, G.G. 1986. Illness behaviour in the elderly. In *Self care and health in old age*. Dean, K., T. Hickey, & B.E. Holstein, Eds. London: Croom Helm. 130-166.

Forrester-Kibunga, K. 1999. *The situation of older women in Tanzania*. Dar es Salaam, Tanzania. London: HelpAge International.

Forrester-Kibunga, K., & Dianga, A. 2000. Victimisation and killing of older women: Witchcraft in Mnagu District, Tanzania. *Southern African Journal of Gerontology*. 9: 29-32.

Foster, G. 2002. Understanding community responses to the situation of children affected by AIDS: Lessons for external agencies. Draft paper prepared for the UNRISD project on HIV/AIDS and development. March 2002.

Fouad, D. 2004. *Role of elderly people in the era of HIV/AIDS in Africa*. Paper read in the African Conference on Ageing, Johannesburg, August 18-20.

Fowler, F.J. 2002. *Survey research methods*. 3rd ed. Thousand Oaks, CA: Sage.

Friedman, I. 2002. Community based health workers. South African Health Review. Durban: Health Systems Trust Report.

Frohlich, J. 2005. The impact of AIDS on the community. In *HIV/AIDS in South Africa*. Abdool Karim, S., & Abdool Karim, Q., Eds. New York: Cambridge University Press,

Fuglesang, A. 1982. *About understanding: ideas and observations on cross-cultural understanding,* Uppsala: Dag Hammarskjold Foundation.

Fuller-Thomson, E., & Minkler, M. 2000. African-American grandparents raising grandchildren: A national profile of demographic and health characteristics. *Health and Social Work Journal.* 25: 109-118.

Gallagher, D., Rappaport, M., Benedict, A. et al. 1985. *Reliability of selected interview and self-report measures with family care givers*. Paper presented in the Gerontological Society of America annual meeting, New Orleans, November.

GAPA. n.d. Grandmothers against AIDS and poverty. Available: www.gapa.org.za. [22, October 2009].

Garbus, A. 2003. *HIV/AIDS in South Africa: Country AIDS analysis project*. San Francisco. University of California Press.

Garenne, M., Tollman, S.M., & Kahn, K. et al. 2006. Fertility trends and net reproduction in Agincourt, rural South Africa: 1992-2004. *Scandanavian Journal of Public Health,* 32(1).

Geffen, N. 2006. How the health minister hurts South Africa. *Business Day*. September 19, 9

Gelfand, D.E. 1994. *Aging and ethnicity: Knowledge and services*. New York: Springer.

George, L.K., & Gwyther, L.K. 1986. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist.* 26: 253-259.

Gerdes, L. 1988. *The developing adult*. 2nd ed. Durban: Butterworths.

Gergen, M.M. 1988. Narrative structures in social explanation. In *Analysing everyday explanation*: *A casebook of methods*. Antaki, C., Ed. Carlifonia: Sage. 94-112.

Giese, S., Meitjies, H., Croke, R., & Chamberlain, R. 2003. *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS. Research report on recommendations.* Cape Town*:* Children's Institute, University of Cape Town.

Gilborn, L.Z., Nyonyintono, R., Kabumbuli., A. et al. 2004. *Making a difference for children affected by AIDS: baseline findings from operations research in Uganda*. Available: www.pop- council.org/pdfs/horizons/orphansbsln-pdf [2006, March 25].

Gilks, W, Richardson, S., Spiegelhalter, D. et al. 1998. *Sexual health and health are: care and support for people with HIV/AIDS in resource poor settings*. Health and Population Occasional paper. London: Department for International Development, UK.

Gleneagles G8 Summit Communique. 2005. Available: http://www.g8.gov.uk/ [2005, November 10].

Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity*. New York: Simon & Shuster.

Goldin, C.S. 1994. Stigmatization and AIDS: Critical issues in public health. *Social Science & Medicine*. 39(9): 1359-1366.

Goodwin, J. 1999. Enhancing the care of people with HIV. *Harvard AIDS Review*. Spring, 16-17.

Gordon, S.M., & Thompson, S. 1995. The changing Epidemiology of human immunodeficiency virus infection in older persons. *American Geriatrics Society Journal*. 43: 7-9

Gould, B., & Huber, U. 2002. HIV/AIDS, poverty and schooling in Tanzania and Uganda. British Society for Population Studies meeting on Poverty and Well-being in HIV/AIDS affected African countries. London, January 8. Available: www.socstats.soton.ac.uk/choices/Gould%20Paper.doc [2005, September 14].

Green, J.C., Caracelli, V.J., & Graham, W.F. 1989. Towards a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis.* 11(3): 255-274.

Griffin, C. 1986. Qualitative methods and female experiences: young women from school to the job market. In *Feminist social psychology: developing theory and practice*. Wilkinson, S., Ed. Milton Keynes: Open University Press. 173-191.

Grundy, E., & Bowling, A. 1991. The Sociology of aging. In: *Psychiatry in the elderly*. Jacob, R., & C. Oppenheimer, Eds. Oxford: Oxford Medical Publications.

Guba, E.G. 1978. *Towards a methodology of naturalistic inquiry in education evaluation*. CSE Monograph Series in Evaluation no. 8. Los Angeles: University of California, Center for the Study of Evaluation.

Gupta, G.R. 2003. Lessons from the past, challenge for the future: An overview of HIV/AID in Africa. Plenary presentation, HIV/AIDS in Africa: what works. Organised by Centre for Global Development and John Snow, Inc.

Gurmessa, M. 1999. *The social effects of AIDS on the elderly*. Addis Ababa: Addis Ababa University.

Guthrie, T. 2000. *Social security for children in South Africa: Options and improvements. Submission to the Committee of Inquiry into Comprehensive Social Security System.* Cape Town: Child Health Policy Institute.

Hansen, K. 1994. The costs of hospitaal care at *Government Health Facilities in Zimbabwe with Special emphasis on HIV/AIDS Patients*. Harare, Zimbabwe: Blair Research Institute, Ministry of Health and Family Welfare.

Hardon, A., Boonmongkon, P., & Streefland, P. et al. 1995. *Applied health research manual. Anthropology of health and health care.* Armsterdam: University of Armsterdam.

Hardy, C. 1999. A vicious cycle: AIDS and gender oppression. Complaints officer, commission on gender. *Women's Month.* August 9: 1.

Harris, D.K. 1990. *Sociology of aging*. 2nd ed. New York: Harper & Row.

Hasselkus, B. 1993. Aging and health. In *Willard and Spackman's Occupational_therapy*. Hopkins, H.L., & H.D. Smith, Eds. Philadelphia: J.B Lippincott.

Harvey, C., Siphambe, H., & Segosebe, E. 2000. *Globalisation and sustainable human development: Progress and challenges for Botswana*. Occasional paper. Geneva. United Nations Development Programme.

Havard, J., & Haslegrave, M. 2000. *Impact of HIV/AIDS on the health professions in developing countries*. Paper presented in the Commonwealth Medical association, Conference on "The HIV/AIDS Crisis: A Commonwealth Response," London, December 7.

Hayslip, B., & Kaminski, P.L. 2005. Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist*. 45(2): 262-270.

Head, J. 1992. *Transformation of the structure of poverty in the struggle for an effective HIV/AIDS policy*. Paper presented in the Ruth First Memorial Colloquium, University of the Western Cape, Cape Town.

Heller, T., & Factor, A. 1993. Aging family caregivers: Support resources and changes in burden and placement desire. *American Journal on Mental Retardation*, 98: 417-426.

HelpAge International. 1998. Ageing: the forgotten development issues. *Ageing and Development.* 1: 1-3.

HelpAge International. 1999a. Making ends meet in Tanzania. *Ageing and Development.* 4. London. HAI.

HelpAge International. 1999b. Summary report on ageing. *Ageing and Development*. London. HAI.

HelpAge International. 2000. A world without poverty: time to include older people? An analysis of current topics in ageing. *Ageing and Development.* 6: 6-7.

HelpAge International. 2001. HIV/AIDS: Why strategies must include older people. An analysis of current topics in ageing. *Ageing and Development*. 8: 6-7

HelpAge International. 2002a. News and analysis of issues affecting the lives of older people. Chronic poverty in South Africa. *Ageing and Development.* 12: 4.

HelpAge International. 2002b. Practical issues in ageing and development. The Second World Assembly on Ageing. *Ageways.* 60: 4-10.

HelpAge International. 2002c. *Participatory research with older people*: *A resource book.* London: HAI.

HelpAge International. 2003a. *Forgotten families. Older people as carers of orphans and vulnerable children.* Policy report. London: HAI.

HelpAge International. 2003b. Raising the issues of rights in Africa. *Ageing and Development.* 14: 6-7.

HelpAge International. 2004a. Last in the queue for treatment? *Ageing and Development*. 16: 9.

HelpAge International. 2004b. *Age and security: how social pensions can deliver effective aid to poor older people and their families*. London: HAI.

HelpAge International. 2004c. Ageing in Africa. Older people must be included in the fight against HIV/AIDS. *Ageways* 7. London. HAI.

HelpAge International. n.d. *Ageing issues in Africa*: *A summary report*. London: HAI.

HelpAge International. 2005a. Isolation in Darfur: Situation analysis report. *Ageing and Development.* 8:1. London. HAI.

HelpAge International. 2005b. Ageing in Africa. Leading global action on ageing. *Ageing and Development.* 23: 8. London. HAI.

HelpAge International**.** 2005c. Older people must be included in the fight against HIV/AIDS. *Ageways* . 40. London. HAI.

HelpAge International (HAI), 2006a. Older women lead response to HIV/AIDS. Available online: www.helpage.org/News/Latestnews/@27680. [2006, April 10].

HelpAge International (HAI), 2006b. *Practical issues in ageing and development, Ageways* (67). London. HAI.

HelpAge International. 2007. News and analysis of issues affecting the lives of older people. *Ageing and Development.* 21: 1-9.

HelpAge International. 2008a. Practical issues in ageing and development. How pensions reduce poverty. *Ageways.* 70: 4-6.

HelpAge International. 2008b. Age demands action; exploding the myth about older persons. *Ageing in Africa*. 32. London. HAI.

HelpAge, 2008c. Social pensions in South Africa. Available: http://www.helpage.org/Researchandpolicy/Socialprotection/PensionWatch/SouthAfrica [2009, September 14].

HelpAge Kenya. 2001. *The impact of HIV/AIDS on older people.* Workshop on HIV/AIDS report back. Nairobi: HelpAge Kenya.

HelpAge Kenya. 2002. *Feasibility study on viable income generating activities for older persons taking care of HIV/AIDS orphans conducted in Ahero, Nyando District Kenya*. Nairobi: HelpAge Kenya.

HelpAge Kenya. 2003. *Report of analysis of communication opportunities for older persons in Kenya*. *An audit phase of older citizen's monitoring project. Nairobi*: HelpAge Kenya.

HelpAge Sudan. 2003. *Older people as caregivers for HIV/AIDS orphans*. London: HelpAge.

Heckman, T., Kochman, A., Sikkema, K. et al. 1999. Depressive symptomatology, daily stressors, and ways of coping among middle age and older adults living with HIV disease. *Journal of Mental Health and Aging*. 5: 311-322.

Heslop, A., & Gorman, M. 2002. *Chronic poverty and older people in the developing World.* Chronic Poverty Research Centre Working Paper no 10. London: HAI.

Heywood, M. 1999. The AIDS epidemic in Africa: Openness and human rights. *SAFAIDS NEWs*. 7(1): 2-7.

Hill, R. 1994. *Families under stress*: *Adjustment to the crises of war separation and reunion*. New York. Harper & Brother.

Hinkle, K.L. 1991. A literature review: HIV seropositivity in the elderly. *Journal of Gerontology Nursing*. 17(10): 12-17.

Hoffman, J. 2004. *A post-modern exploration of intergenerational practices in Africa: a framework towards programming*. Paper presented in the African Conference on Ageing. Johannesburg, August 18-20.

Holmshaw, M. 1992. When will they ever learn…? *Current AIDS Literature*. 5(5): 149-150.

Homans, G.C. 1958. Social behaviour as exchange. *American Journal of Sociology*, 63(6):597-606.

Homsy, R. 1997. Involving traditional healers in AIDS education and counselling in sub-Saharan Africa: A review. *AIDS*. 11: 217-225.

Horizons. 2003. *The involvement of people living with HIV/AIDS, in Community-based Prevention, Care and Support Programmes in Developing Countries*: A multi-country Diagnostic Study.

Horizons. 2004a. *Expanding care and support in South India: Scaling up YRG care's patient – centered approach.* International HIV/AIDS Alliance Horizons Programme. Final Report. Washington DC**.**

Horizons. 2004b. '*Our hearts are willing, but …' Challenges of elderly caregivers in rural Kenya*. Research update. Washington, D.C.: USAID.

Horizons. 2005. *Providing Psychosocial Support to AIDS affected Children. Operations research informs programmes in Zimbabwe and Rwanda*. Research Report. Washington DC.

Horizons. 2006. *Strengthening HIV service delivery. Studies focus on care and treatment in India, Kenya and South Africa*. Horizons Report. Available: www.popcouncil.org/pfs/horizons/sacssymp.pdf [2006, July 7].

Horizons. 2007. Closer to home. Community-based activities complement PMTCT programmes in Kenya. Horizons Report. Washington DC.

House, E.R. 1994. Integrating the quantitative and qualitative. *New Directions for Programme Evaluation*. 61: 13-23.

Householam, C. 2009. *Message from the head of department to staff*. Official news letter of the Western Cape Department of Health. September pp. 3.

Howe, K.R. 1988. Against the quantitative-qualitative incompatability thesis or dogmas die hard. *Educational Researcher*. 17: 10-16.

Huber, B. 2004. Opening address. African Conference on Ageing. Johannesburg, August 18-20.

Hudelson, P.M. 1996. *Qualitative research for health programmes*. Geneva: WHO.

Human Development Report. 2000. *The political economy of transformation and human development. South Africa*. Available: www.undp.org.za/sahdr2000/hdr.chapter%20. [2008, February 7].

Human Development Report. 2007/08. *Country fact sheet*. Mbabane, Swaziland.

Humm, M. 1990. The dictionary of feminist theory. *Columbus: Ohio State University Press*.

Hunter, S.S. 1990. Orphans as a window on the AIDS epidemic in Sub-Saharan Africa: initial results and implications of a study in Uganda. *Social Science & Medicine*. 31(6): 681-690.

Human Rights Watch Kenya. 2005. *Country summary report*. Nairobi: KHRW

International AIDS Vaccine Initiative. 2003. *Report on the global AIDS epidemic*. 4th global report. Geneva: UNAIDS.

International HIV/AIDS Alliance. 2002. *Participation in the Global Fund: a review paper*. London. Available: www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Policy/NGO%20Participation.pdf [2006, October 29].

International HIV/AIDS Alliance. 2003. *Building blocks: Africa wide briefing notes -- psychosocial support*. Brighton : International HIV/AIDS Alliance.

International Labour Organisation. 1942. *Approaches to social security*. Montreal: ILO.
The ANNALS of the American Academy of Political and Social Science. 1942; 222: 237

Jackson, H. 2002. *AIDS Africa: Continent in crisis*. Harare: SAFAIDS.

Jackson, H., & Anderson, S. 2001. Home care for people with AIDS. In *HIV/AIDS prevention and care in resource constrained settings: A handbook for the design and management of programmes*. Lamptey, P.R., & Gayle, H.D. Eds. Arlington, VA: Family Health International.

Jackson, H., & Kerkoven, R. 1995. Developing AIDS care in Zimbabwe: a case for residential community centers? *AIDS Care*. 7(5): 663-673.

Jacoby, A. 1994. Felt versus enacted stigma: A concept revisited, evidence from a study of people with epilepsy in remission. *Social Science & Medicine*. 38(2): 269-274.

James, K. 2004. *HIV/AIDS and the changing role of the aged. Understanding the role, constraints and consequences for the elderly as providers of education to children orphaned by HIV/AIDS*. Paper presented in the international conference "Rapid ageing and the changing role of the elderly in African households" Johannesburg, 18-20 August**.**

Jamil, I., & Muriisa, R. 2004. *Building social capital in Uganda: the role of NGOs in mitigating HIV/AIDS challenges*. Paper presented in the conference of the International Society for Third Sector Research (ISTR), Toronto.

Janicki, M.P., & MacEchron, A.E. 1984. Residential, health, and social service needs of elderly developmentally disabled persons. *Gerontologist.* 24: 128-137.

Jayaraman, K.S. 1998. Indian state plans compulsory HIV testing, segregation and branding. *Nature Medicine*. 4(4): 378.

Jazdowska, N. 1992. *Elderly women caring for orphans and people with AIDS, Ward Six, Hurungwe District*. Harare, Zimbabwe: HelpAge Zimbabwe.

Jedlovsky, V., & Fleischman J.K. 2000. Pneumocytis carinii pneumonia as the first presentation of HIV infection in patients older than fifty. *AIDS Patient Care*. Jamaica: Mount Sinai Services, Queens Hospital Center.

Jewkes, R., Abrahams., N., & Mvo, Z. 1998. Why do nurses abuse patients? Reflections from South African obstetric services. *Social Science & Medicine*. 47(11): 1781-1795.

Jick, T.D. 1979. Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly*, 24: 602-611.

Johansson, C. 2008. Human development report shocks South Africa. Available: http://www.afrol.com/articles/16932. [2008, March 25].

Johnson, B.K. 1996. Older adults and sexuality: a multidimensional perspective. *Gerontological Nursing*. 22: 6-15.

Johnson, S., Shierhout, G., Steinberg, M. et al. 2002. AIDS in the household. In *South African Health Review*. Ijumba, P., A. Ntuli, & P. Barron, Eds. Durban: Health Systems Trust, 203 –216.

Johnston, A.G. 2001. *Twelve key messages on HIV/AIDS. A briefing paper to US Ambassadors in Africa*. Report prepared by the Policy Project for the US Agency for International Development. Washington D.C.

Jones, S. 1996. Individual mobility and domestic fluidity. In *Marriage and family life in South Africa: research priorities*. Pretoria: Human Sciences Research Council.

Joubert, J.D., Bradshaw, D. 2000. *Burden of disease in older persons in South Africa*. Parow Valley: South Africa. Medical Research Council, Burden of Disease Research Unit.

Joubert, J., & Bradshaw, D. 2004. Health of older persons: Leading single causes of death in persons 60+, 2000. *SA Health Review*, Health Systems Trust. 147– 162. Available: www.//search.sabinet.co.za/WebZ/images/ejour/healthr/healthr_2003_a11.pdf:sessionid=0:bad=http://search.sabinet.co.za/ejour/ejour_badsearch.html:portal=ejournal:[2007, October 22].

Joubert, J.D., & Bradshaw, D. 2005. Population ageing and health challenges in South Africa. In *Chronic diseases of lifestyle in South Africa since 1995-2005*. Technical Report. Parow Valley: SA Medical Research Council.

Joubert, J.D., Swart, D., & Reddy, P. 1998. Knowledge, perceptions and needs of older persons with reference to 1999, the International Year of Older Persons: A qualitative study in the Eastern Cape. Unpublished. Parow Valley: SA Medical Research Council.

Joubert, J.D., Reddy, P., & Bryan, W. 2002. Informal care in South Africa: A carer perspective. Final report. Parow Valley: SA Medical Research Council.

Kahana, E., & Kahana, B. 2001. Successful aging among people with HIV/AIDS. *Journal of Clinical Epidemiology*. 52: S53-54.

Kaleeba, N., Kalibala, S., Kaseje, M. et al. 1997. Participatory evaluation of counseling, medical and social services of AIDS Support Organisation (TASO) in Uganda. *AIDS Care*. 9(1): 13-26.

Kaleeba, N., Ray, S., & Willmore, B. 1991. *We miss you all: AIDS in the family*. Harare: Women and AIDS Support Network.

Kart, C. 1981. Experiencing symptoms: Attributions and misattributions of illness among the aged. In *Elderly patients and their doctors*. Huang, M., Ed. New York: Sage. 70-78.

Kasternbaum, R. 1993. *Encyclopeadia of adult development*. Arizona, Orynx Press.

Katzenellenbogen, J., Joubert, G., & Yach, D. 1991. *Introductory manual for Epidemiology in South Africa*. Parow Valley: SA Medical Research Council.

Kelley, H.H., & Thibault, W.A. 1978. *Interpersonal relations: A theory of interdependence*. New York: John Wiley.

Kelley, S.J. 1993. Caregiver stress in grandparents raising grandchildren. *IMAGE: Journal of Nursing Scholarship*. 25: 331-337.

Kent, M.M., & Haub, C. 2005. Global demographic divide, *Population Bulletin*. 60(4). Washington, D.C.: Population Reference Bureau.

Kenya National HIV/AIDS Strategic Plan. 2005/6 - 2009/10. *A call to action*. Nairobi: National AIDS Control Council.

Kerlinger, F. 1964. *Foundations of behavioral research*. 3rd ed. New York: Holt, Rinehart & Winston.

Kespichyawattana, J., & Van Landingham, M. 2003. Effects of co-residence and caregiving on health of Thai parents of adult children with AIDS. *Journal of Nursing Scholarship*, 35(3): 217- 224.

Ketetu. n.d. Girls' and Women's Education in Kenya. Nairobi. UNESCO. Available: http://www.education.nairobi-unesco.org/index.php?option=com_content&task=view&id=799&Itemid=56 [23, October 2008]

Kiely, J., & Hodgson, G. 1990. Stress in prison service: The benefits of exercise programmes. *Human Relations*. 43: 551-72.

Kish, L. 1965. *Survey sampling*, New York: John Wiley.

Kish, L. 1987. *Statistical design for research*, New York: John Wiley.

Kimuna, S.R. 2004. *Living arrangements of older adults in Zimbabwe*: *Their socioeconomic and socio-demographic conditions*. Presentation in the African Conference on Ageing. Johannesburg, August 18-20.

Kinsella, K., & Ferreira, M. 1997. *Aging trends*: *South Africa*. Washington, D.C.: U.S. Bureau of Census.

Kinsella, K., & Phillips, D. 2005. The global ageing: The challenge of success. *Population Bulletin*. 60(1): 6- 42.

Kirby, D. 2002. The impact of schools and school programmes upon adolescent sexual behaviour. Journal of Sex Research. 39: 27-33.

Knodel, J. 2005. Researching the impact of the AIDS epidemic on older-age parents in Africa: Lessons from studies in Thailand. Journal of the *British Society of Gerontology*. 15(2): 16-22.

Knodel, J., & Im-em, W. 2004. The economic consequences of parents of losing an adult child to AIDS: Evidence from Thailand. *Social Science & Medicine*. 59(5): 987-1001.

Knodel, J., & Saengtienchai, S. 2001. *Parents providing care to adult sons and daughters in Thailand. UNAIDS case study*. Geneva: UNAIDS.

Knodel, J., & Van Landingham, M. 2000. Children and older persons: AIDS' unseen victims. *American Journal of Public Health*. 90(7): 1024-1025.

Knodel, J., Watkins, S., & Van Landingham, M. 2002. *AIDS and older persons: An international perspective*. Population Studies Report No. 02-495. Ann Arbor, MI: Population Studies Center, University of Michigan.

Knodel, J., Watkins, S., & Van Landingham, M. 2003. AIDS and older persons: an international perspective. *Journal of Acquired Immune Deficiency Syndrome.* 33(2): S153-65.

Knodel, J., Zimmer, Z., Sovan-Kim, K. et al. 2006. *The impact of AIDS on older-age parents in Cambodia*. Report 06-594. Ann Arbor: Population Studies Center, University of Michigan.

Kondel-Lule, J.K., Sewankambo, N., Mawer, et al. 1996. *The impact of AIDS on families in Rakai District, Uganda*. Paper presented in the XIth International Conference on AIDS, Vancouver.

Kok, P., & Collinson, M. 2006. *Migration and urbanization in South Africa*. Human Sciences Research Council. Pretoria.

Kongsin, S., & Watts, C.H. 2000. *Conducting a household survey on economic impact of chronic HIV/AIDS morbidity in rural Thailand. Methodological issues*. Paper presented in the AIDS and Economics Symposium, Durban, July, 7-8.

Krippendorf, K. 2004. *Content analysis: An introduction to its methodology*. 2nd ed. Thousand Oaks, CA: Sage.

Kumar, K. 1986. *Conducting key informant interviews in developing countries*. AID Programme Design and Evaluation Methodology Report No.13. Washington, D.C.: Agency for International Development.

Kutz, S.J. 2004. Social capital and health. *British Medical Bulletin*, 69: 61–73.

Lang, S.S. 2005. In Africa, children as young as 9 are heading households and turning to other children for help. Chronicles, University of Cornell. Available: http://www.news.cornell.edu/stories/Nov05/africa.orphan.heads.ssl.html. [2008, November 29].

Last, J.M. 1988. *Ethics and Epidemiology*. World Health Report. Geneva: WHO. 22-24.

Lauer, J. 1999. The ageing face of AIDS. Jacksonville Medicine. *American Journal of Geriatrics and Social Sciences*. 17(9):39-42.

Lee, C.C., Leo, Y.S., Snodgras, I. et al. 1997. The demography, clinical manifestations and natural history of human immunodeficiency virus (HIV) in infection in an older population in Singapore. *Journal of Association of Nurses in AIDS Care*, 20: 3.

Lee, G.R. 1980. Kinship in the seventies: a decade review of research and theory. *Journal of Marriage and the Family*. 42: 923-934.

Legido-Quigley, H. 2003. *The South African old age pension: Exploring the role on poverty alleviation in households affected by HIV/AIDS*. Paper presented in the 4th International Research Conference on Social Security Antwerp, Belgium 5-7 May, 5-7.

Lenton, C., Hawkins, K., & Jani, R. 2003. *Evaluation of targeted interventions in reduction of HIV transmission in five states in India*. London: Department of International Development (DFID).

Lesar, S., Gerber, M., & Semmel, M. 1995. HIV infection in children: Family stress, social support, and adaptation. *Exceptional Children*. 62: 224-236.

Lesthaeghe, R. 1983. A century of demographic and culture in Western Europe: an explanation of underlying dimensions. *Population and Development Review*. 9: 411-435.

Lesotho Council of NGOs. 2006. Human rights violations under scrutiny in Lesotho. Available: www.lecongo.org.ls/newsletters/HR_Violation_Scrutiny.php [2008, February 1].

Levinson, B.A. 1994. *The cultural production of the educated person: critical ethnographies*. New York: Albany.

Lerman, H. 1990. *Feminist ethics in psychotherapy*. New York: Springer.

Lieberman, R. 2000. HIV in older Americans: an epidemiological perspective. *Journal of Midwifery and Women's Health*. 45(2):176-182.

Liese, B., Blanchet, N., & Dussault, G. 2003. *The human resource crisis in health services in sub-Sahara Africa*. Washington, D.C.: World Bank.

Linsk, H. 1994. HIV and the elderly. HIV/AIDS. *Families in Society*. 75: 362-372.

Lisk, F. 2002. *Labour market and employment implications of HIV/AIDS*. Working Paper 1. Geneva: ILO Programme on HIV/AIDS and the World of Work.

Lohmann, R. A. 1992. *The commons: new perspectives on non-profit organizations and voluntary action*. CA: Jossey-Bass.

Luggen, A.S. 1996. AIDS in the older adult. In *Geriatric Nursing core curriculum for gerontological nursing*. Luggen, A.S., Ed. St. Louis: Mosby.

Lund, F. 1999. Understanding South African social security through recent household surveys: New opportunities and continuing gaps. *Development Southern Africa*. 16(1): 55-57.

Lurie, M.N., Harrison, A., & Wilkinson, D. et al. 1997. Circular migration and sexual networking in rural KwaZulu-Natal: implications for the spread of HIV and other sexually transmitted diseases. *Health in Transition Review*, 17(3): 17-27.

Lurie, M.N., Williams, B.G., Zuma K. et al. 2003. The impact of migration on HIV-1 transmission in South Africa: A study of migrant and non-migrant men and their partners. *Sexually Transmitted Diseases*. 30: 149-156.

Lusk, D., Huffman, S.L., & O' Gara, C. 2004. Assessment and improvement of care for AIDS-affected children under age 5. Available: www.pronutrition.org/pubview.php/54 [2005, October 30].

Maartens, G. 2002. HIV/AIDS in South Africa. In *Prevention of opportunistic infections in adults*. Abdool-Karim, S & Q. Abdool-Karim. Eds. New York: Cambridge University Press. 454-462.

MacNeil, J.M. & Anderson, S. 1998. "Beyond the dichotomy: linking HIV prevention with care." *AIDS Care*. 12(2): S19-26.

Maher, J. 2006. HIV and AIDS and older people in developing countries. *Global Ageing*. 4(2): 14-32.

Maitse, T. 2001. *Racism, xenophobia and gender in the context of the world.* Paper presented in the World Conference on Gender and Racism and Related Intolerances, Durban, South Africa.

Makiwane, M., Schneider, M., & Gopane, M. 2004. *Experiences and needs of older persons in Mpumalanga*. Report written for the Human Sciences Research Council and Department of Social Services, Mpumalanga.

Makubalo, L., Netshidzivhani, P., Mahlasela, L. et al. 2004. *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa*. Pretoria: Department of Health.

Malcolm, A., Aggleton, P., Bronman, M. et al. 1998. HIV related stigmatization and discrimination: Its forms and contexts. *Critical Public Health*. 8(4): 321-333.

Malone, M.A. 1998. HIV-positive women over fifty: How they cope. *AIDS Patient Care and STDs*. 12(8): 639.

Maluwa, M. 2000. *Background note: HIV/AIDS and human rights.* Presentation in the Regional NORAD/SIDA Meeting on Strengthening the Integration of HIV/AIDS into Development Cooperation. Zomba, Malawi, November 16-17.

Mamdhani, M. 2001. *When victims become killers. Colonialism, nativism, and the genocide in Rwanda*. Cape Town. David Philip.

Manby, B. 2004. The African Union, NEPAD, and human rights: The missing agenda. *Human Rights Quarterly*. 26(4): 983-1027.

Mandela, N. 2000. Closing address by former President. AIDS *Bulletin*, 99(3): 3-11.

Mann, J.M . 1989. *AIDS:* A worldwide pandemic. In *Current topics of AIDS*, 2. Gottlieb, M.S., D.J Jeffries, D, Mildivan, Pinching, A.J., & T.C Quinn, Eds. Geneva: John Wiley.

Marcfarlane, M. n.d. Doctors not enough in South Africa. Available: www.thetidenews.com/article.aspx?qrDate. [2006, April 19].

Marcoux, A. 2001. *Ageing rural populations in the developing countries: patterns, causes and implications.* Paper presented in the United Nations' International Conference on Ageing Populations in the Context of the Family, Kitakyushu, Ageing and the family, New York.

Mason, A. 2001. Aging population tied to shrinking work force, slower economic growth. *East-West Center Observer*. 5(1): 2-5.

Masulit, S.P. 1998. Assessment of a community-based health programme for the elderly: implications for future initiatives. Unpublished MSc dissertation. Philippines: De La Salle University.

Mathews, C. 2005. Reducing sexual risk behaviours: Theory and research, successes and challenges. In *HIV/AIDS in South Africa*. A, Karim, & Q. Karim, Eds. New York: Cambridge University Press. 143-163.

Matshalaga, R.N., & Powell, G. 2002. Mass orphanhood in the era of HIV/AIDS. Bold support for alleviation of poverty and education may avert a social disaster. *British Medical Journal*. 324: 185-86.

May, J. 2003. *Chronic poverty and older people in South Africa*. Durban: University of KwaZulu-Natal.

Mayan, M.J. 2001. *An introduction to qualitative methods*: *A training module for students and professionals*. Alberta, Canada: International Institute for Qualitative Methodology.

Mazhani, L., Sekgoma, B., & Mokopakgosi, O. 2000. Report of mid-term review of the prevention of MTCT programme of Botswana Ministry of Health and UNICEF. Gaberone: Ministry of Health.

Mba, C.J. 2004. *Population ageing and poverty in rural Ghana*. Paper presented in the African Conference on Ageing, Johannesburg, August 18–20.

Mbali, M. 2002. Mbeki's denialism and the ghosts of apartheid and colonialism for post Apartheid AIDS policy-making. Public Health Journal Club seminar paper, University of Natal, Durban, May 3.

Mbazira, C. 2006. *Realising socio-economic rights in the South African Constitution: The obligations of local government. A guide for municipalities*. Cape Town: Community Law Centre, University of the Western Cape.

Mbola, B. 2008. Social grant spending increased. Midterm Budget speech by minister of finance, 2008. *BuaNews*, 21 February: 2

McCoy, D., & Engelbrecht, B. 1999. Establishing the District Health System. *South African Health Review*. Durban: Health Systems Trust.

Mckenry, P. & Price, S. 1994. *Families and changes: Coping with stressful events*. Thousand Oaks, CA: Sage.

Mcqueen, D. 1992. Understanding sexual behaviour. *AIDS*. 6: 329-330.

Meadows, J., Le-Marechal, K., & Catalan, J. 1999-2001. The burden of care: the impact of HIV-associated dementia on caregivers. *AIDS-Patient-Care-STDs*.13(1): 47-56.

Mercy, J.A. 1993. Public Health policy for preventing violence. *Health Affairs*. 12: 7-29.

Merriam, S.B. 1991. *Case study research in education*. San Francisco: Jossey-Bass.

Messkob, M. 1999. Crisis of ageing in less developed countries: Too much consumption or too little production? *Development and Change*. 5(1): 2-5.

Meyer, S. 2002. *The influence of parental incomes on children's outcomes*. New Zealand**:** Ministry of Social Development.

Meyers, D.T. 2000. Feminism and women's autonomy: The challenge of female genital cutting. *Metaphilosophy*, 31(5): 469-491.

Michael, A. 2007. Webster's new world College Dictionary. *New York. John Wiley.*

Miles, M., & Huberman, A.M. 1984. *Qualitative data analysis: A source book of new methods.* London: Sage.

Miller, D. 2000. *Dying to care? Work, stress and burnout in HIV/AIDS*. London and New York: Routledge.

Minkler, M., Roe., K.M., & Price, M. 1992. The physical and emotional health of grandmothers raising grandchildren in the crack cocaine epidemic. *Gerontologist.* 32: 752-761.

Minkler, M., & Roe, K.M. 1993. *Grandmothers as caregivers: Raising children of the crack cocaine epidemic.* Newbury Park, CA: Sage.

Mishler, E. 1986. *Research interviewing: context and narrative*. Cambridge, MA: Harvard University Press.

Mitchell, M., & Jolly, J. 1996. *Research design explained.* 3rd ed. New York: Harcourt Brace College. USA.

Moderator. 2008. Minister of Health and Others vs Treatment Action Campaign and Others. Available: http://www.constitutionalcourt.org.za/uhtbin/hyperion-image/S-CCT8-02. [2008, December 28].

Mohaty, C.T. 2003. *Feminism without borders: Decolonizing theory, practicing solidarity*. Durham, NC. Duke University Press.

Molm, L.D. 2001. Theories of social exchange network. In *Handbook of social theory*. Ritzer, G., & B, Smart, Eds. London: Sage, pp. 260-272.

Mϕller, V., & Ferreira, M. 2003. Getting by… Benefits of non-contributory pension income for older South African households. Cape Town: Institute of Ageing in Africa, University of Cape Town.

Mϕller, V., & Sotshongaye, A. 1996. My family eats this money too: pension sharing and self-respect among Zulu grandmothers. *South African Journal of Gerontology*. 5(2): 9-19.

Monasch, R., & Clark, F. 2004. Grandparents' growing role as carers. *Ageing and Development,* London: HAI. Available: http://www.avert.org/older-people.htm .
[2008, October 26].

Morgan, D. 1998. Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research*. 8(3): 362-376.

Morse, J.M. 1991. Approaches to quantitative-qualitative methodological triangulation. *Nursing Research*. 4(1): 120-123.

Msimang, S. 2003. UNIFEM Cape Town Consultation, in partnership with the Positive Women's Network, and the Youth Against AIDS Network, May 2003 Cape Town.

Mtei, L.N., & Pallagyo, K.P. 2001. HIV infection in elderly medical patients. *East African Medical Journal.* 78(3): 144-147.

Morton, L.R. 2002. Building local knowledge for developing health policy through key informant Interviews. *Journal of Extension*. 40(1): 1-9.

Moustakas, C. 1994. *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Mpanju-Shumbusho, W. 2003. Building capacity and community resilience to HIV. Presentation in the Planning Workshop for Increasing Access to Care and Treatment for PLWHA, Harare, June, 7-10.

Mupedziswa, R. 1997. AIDS and older Zimbabweans: Who will care for the carers? *South African Journal of Gerontology*. 6(2): 9-12.

Mustafa, K. 2004. Policy workshop Opening statement on behalf of the United Nations Namibia Country Team. United Nations Department of Economic and Social Affairs, Windhoek, January, 28-30.

Mwagi, F.W. 1994. Care for HIV positive orphans at Nyumbani hospice in Kenya. International Conference. *AIDS*, 10(2): 400.

Mwape, G. 2003. *The role of older people as carers of orphans and vulnerable children in Katuba area of Chilombo district, Zambia*. London: International HIV/AIDS Alliance.

Nampanya-Serpell, N. 2000. *Social and economic risk factors for HIV/AIDS-affected families in Zambia*. Paper presented in the AIDS and Economics Symposium, Durban, July, 7-8.

Narain, J.P., Chela, C., & Van Praag, E. 1998. *Planning and implementing HIV/AIDS care programmes*: *A step by step approach*: WHO. Regional Office for South-East Asia.

Nattras, N. 2005. Trading off income and health?: AIDS and the disability grant in South Africa. *Journal for Social Policy*. 35(1): 3-19.

Nesbary, D.K. 2000. *Survey research and the world wide web*. Boston: Allyn & Bacon.

Neugarten, B. 1971. Grow old along with me! The best is yet to be. *Psychology Today*. 5: 45-48 & 79-81.

Newman, I., & Benz, C.R. 1998. *Qualitative-quantitative research methodology*: *Exploring the interactive continuum*. Carbondale: Southern Illinois University Press.

New Partnership for Africa's Development (NEPAD). 2001. New Partnership for Africa's Development document. Available: www.dfa.gov.za/au.nepadbrief.htm, [2008, April 6].

Ngalula, J., Urassa, M., Mwaluko. G. et al. 2001. Health service use and household expenditure during terminal illness due to AIDS in rural Tanzania. *Tropical Medicine & International Health*. 7(10): 873-877.

Nhongo, T. 2003. Speech at the launch of the African Union Policy Framework and Plan of Action on Ageing. Addis Ababa, Ethiopia.

Nhongo, T. 2004. *Rapid ageing and the changing role of the elderly in African households*. Paper presented in the African Conference on Ageing. Johannesburg. August, 18-20.

Niehaus, I. 2001. *Witchcraft, power and politics: Exploring the occult in the South African Lowveld*. London: Pluto Press.

Nightingale, D.S., & Rossman, S.B. 1994. Managing field data collection from start to finish. In *Handbook of practical programme evaluation*. Wholey, J.S., H.P. Hatry, & K.E. Newcomer, Eds. San Fransisco: Jossey-Bass.

NMG-Levy Consultants and Actuaries. 2002. *AIDS: The private sector challenge*. Cape Town.

Nokes, K.L., Rivero-Mendez, M., Valencial, C.P. et al. 2006. Socio-demographic and other characteristics in persons 50 years and older with HIV/AIDS in five countries. Montreal: International Federation on Ageing. 5-13.

Noumbissi, A. 2004. *Poverty among the elderly in South Africa*. Paper presented in the African conference on Ageing. Johannesburg, August. 18-20.

Nsutebu, F.E. 2001. Scaling up HIV/AIDS and TB home-based care: Lessons from Zambia. *Health Policy Plan*, 16(3): 240-247.

Ntozi, J., & Nakayiwa, S. 1999. AIDS in Uganda: How has the household coped with the epidemic? In *The continuing HIV/AIDS epidemic in Africa: Response and coping strategies.*

Ntozi, P.M., Ahimbisibwe, F.E., & Odwee, J.O et al., 1999. *Orphan care: The role of the extended family in northern Uganda*. *The continuing African HIV/AIDS epidemic*, *AIDS Care*, 22: 225-236.

Orubuloye, I.O., J.C. Caldwell, & J. Ntozi, Eds. Canberra: Australian National University Health Transition Centre.

Nusberg, C. 2006. Age, ageism, and HIV/AIDS. *Global Ageing: Issues and Actions.* 4(2): 2-3.

Nxusani, N.V. 2004. Late life migration and adjustment of older persons: between the Eastern Cape and Western Cape provinces in South Africa. In Untold stories: Giving voice to

the lives of older persons in new South Africa. An anthology. Ferreira, M., & Van Dongen, Eds. Cape Town: Institute of Ageing in Africa, University of Cape Town.

Nyblade, L. 2003. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. Washington, D.C.: International Centre for Research on Women.

Nzimande, S.V. 1996. Family structure and support systems in black communities. In *Marriage and family in South Africa, family structure and support systems*. Pretoria: Human Sciences Research Council.

Office of Population Censuses and Surveys (OPCS). 1989. *General household survey,* 1986. London: HMSO.

Ohuche, N.M., & Littrell, J.M. 1989. Igbo students attitudes toward supporting aged parents. *International Journal on Ageing and Human Development.* 29(4): 259-267.

Ogden, J., Esim, S., & Grown, C. 2004. *Expanding the care continuum for HIV/AIDS: Bringing carers into focus*. Horizon Report. Washington, D.C.: International Center for Research on Women.

Okoye, U.O. 2004. *The erosion of traditional forms of care for the elderly and its implication for the elderly in Nigeria*. Paper presented in the Africa Conference on Ageing. Johannesburg. August 18-20.

Oleja, J.M. 1999. Assessing community attitude towards home based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*. 24(3): 187-199.

Olshansky, S. 1962. Chronic sorrow: A response to having a mentally defective child. *Social Casework*. 63: 190-193.

Onyx, J., & Leonard, R. 2002. *Transforming civil society, citizenship and governance: The third sector in an era of global (dis) order*. Paper presented in the 5th International Conference on governance. Cape Town. July 7-10.

Organisation of African Union (OAU). 1980. *Lagos Plan of Action for the Economic Development of Africa* 1980-2000. Geneva. Institute of Labour Studies, 3, 7.

Organisation of African Union (OAU). 1981. African (Banjul) Charter on Human and People's Rights, 1981 Declaration on Human and People's Rights. Nairobi. Available: *www.preventgbvafrica.org/content/african-banjul-charter-human-and-peoples-rights-1981-declaration-human-and-peopl... [2007, September 21]*.

Orner, P. 2006. Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*. 18(3): 236-240.

Osborne, C. 1996. HIV/AIDS in resource-poor settings: comprehensive care across a continuum. *AIDS*. 10(3): 61-67.

PAHO/WHO. 2000. *Building blocks: Comprehensive care guidelines for persons living with HIV/AIDS. A summary report*. Available:

http://www.paho.org/english/hcp/hca/BuildingBlocks.pdf [2006, July 23].

Page, S.L.J. 2000. *Longevity in HIV+ mothers: the need to promote good health, household food security and economic empowerment to ensure family survival in Southern Africa*. Paper presented in the UN Expert Group Meeting on the HIV/AIDS Pandemic and its Gender Implications, Windhoek. November 13-17.

PANOS. 1990. *Triple jeopardy: Women and AIDS*. London: PANOS Institute.

Parker, W., & Kelly, K. 2000. Communities of practice. Contextual mediators of youth response to HIV/AIDS. Sentinel site monitoring and evaluation project. Centre for AIDS Development, Research and Evaluation. Available: www.cadre.org.za. [2006, January 4] .

Parker, R.G., Eason, D., & Klein, C.H. 2000. Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS*. 14(1): 22-32.

Pathfinder International. n.d. *Responding to HIV/AIDS. Community Home Based Care*. A Fact Sheet.

Programme for Appropriate Technology in Health (PATH). 1994. A response to recent questions about latex condom effectiveness in preventing sexual transmission of the AIDS virus. Condoms: How effective are they? *SAFAIDS News*. 3(4):14.

Patton, M.Q. 1990. *Qualitative evaluation and research methods*. 2nd ed. London: Sage.

Peltzer, K., Mngqundaniso, C.N., & Petros, S.G. 2005. A controlled study of an HIV/AIDS/STI/TB intervention with traditional healers in KwaZulu-Natal, South Africa. *AIDS and Behavior*. 10(6): 83-690.

Peltzer, K., Phaswana-Mafuya, N., Petros, S.G. et al. n.d. Health care quality assurance: Primary Health Care service delivery in South Africa. Report prepared for the European Union Department of Health (South Africa).

Perlman, M. 1988. The fine line between knowledge and terror. *The Weekly Mail*, December 10-11. 15-22.

Petros, S.G., Arhihenbua, C., & Ramlagan, S. et al. 2005. HIV/AIDS "othering" in South Africa: the blame goes on. *Culture, Health & Sexuality*. 8(1): 67-77.

Phaswana-Mafuya, N., Petros, S.G., Peltzer. K. et al. 2008. Health care quality assurance: Primary Health Care service delivery in South Africa. *International Journal of Health Care Quality Assurance*. 21(6): 611-624.

Phiri, S.N., Foster, G., & Nzima, M. 2001. *A study to explore ways to scale up effective, sustainable community mobilization interventions to mitigate the impact of HIV/AIDS on children and families*. Paper prepared for the displace Children and Orphans Fund of USAID. March 21.

Phororo, H. 2000. *Why the private sector should be concerned about HIV/AIDS*. Occasional Paper 1. Windhoek: Hans Seidal Foundation of Namibia.

Pillay, Y., Mzimba, M., & Barron, P. 1998. *Handbook for district managers*. Pretoria: Department of Health (South Africa).

Pillay, Y., McCoy, D., & Asia, B. 2001. *The District Health System in South Africa: Progress made and next steps*. Available: http://www.doh.gov.za/docs/policy/dhsystem.html [2005, June 18].

Pisani, E. 1999. AIDS into the 21st Century: Some critical consideration. *SAfAIDS News.* 7(4): 2-10.

Poggenpoel, M. 1998. Data analysis in qualitative research. In *Research at grassroots. A primer for the caring professions*. De Vos, A.S., Ed. Pretoria: van Schaik. 334-353.

Population Council. 2000. Syndromic method poor at detecting STIs in women. *Population Briefs.* 6(1): 4.

Porter, K., & Zaba, B. 2004. The empirical evidence for the impact of HIV on adult mortality in the developing world: data from serological studies. *AIDS*. 18 (2): S9-S17.

Portney, L.G., & Walkins, M.R. 1993. *Foundations of clinical research: Applications to practice*. East Norway, CT: Appleton & Lange.

Potter, J., & Wetherell, M. 1987. *Discourse and social psychology: beyond attitudes and behaviour*. London: Sage.

Poundstone, K.E., Strathdee, S.A., & Celentano, D.D. et al. 2004. The social epidemiology of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. *Epidemiologic Reviews.* 26: 22-35.

Prince, B., Kleintjies, S., & Cloete, A. et al. 2005. Contextualising gender mainstreaming. In *Gender Mainstreaming in HIV/AIDS*. Seminar Proceedings. 7th AIDS Impact conference. Cape Town. Human Sciences Research Council.

Procaare, H.C. 2001. Stigma and care: setting the scene. Available: www.old.healthnet.org/programs/procaare-hma/procaare.200109/msg00019.html. [2006, December 23].

Putnam, R.D. 1993. *Making democracy work*. Princeton, NJ: Princeton University Press.

Putzel, J. 2003. Institutionalizing an emergency response*: HIV/AIDS and governance in Uganda and Senegal*. A report submitted to the Department for International Development, UK, May.

Qwane, E. 2001. An analysis of reasons for wanting and not wanting to disclose HIV status. *South African AIDS information dissemination service News (SAfAIDS)*, 96(6): 280-282.

Rabelo, F.M. 2004. *The impact of ageing on the future of civil service*. Presentation in the Ad-hoc Expert Group Meeting "Unlocking the Human Potential for Public Sector Performance", Florence, May 6-8.

Rajan, S.I., Perera, M., & Begum, S. 2004. *Pensions and social security policies for elderly in South Asia*. Paper read in the African Conference on Ageing. Johannesburg, August18-20.

Ray, S., & Mataure, P. 2000. *The Mabvuku Hospice and Home Care Project Evaluation* 2000, Harare: Evaluation Report, SAfAIDS.

Rawlston, V. 2000. *The impact of social security on child poverty*. Special Research Report (SRR-01-2000) Washington, D.C.: National Urban League.

Rebouche', R. 2006. Labour, land and women's rights in Africa: Challenges for the New Protocol on the Rights of Women. *Harvard Human Journal*. 19.

Rees, M. 1989. Miners, refugees, soldiers at risk. *WorldAIDS*, 4(6).

Rehle, T.M. & Shisana, O. 2003. Epidemiological and demographic HIV/AIDS projections. *South Africa. African Journal of AIDS Research.* 2(1): 1-8.

Richardson, J. J. & Jordan, A. G. 1983. Overcrowded policymaking: Some British and European reflections. *Policy Sciences.* 15(3): 247-268.

Rifkin, S., & Walt, G. 1986. Why health improves: Defining the issues concerning comprehensive primary health care. *Social Science & Medicine*. 23: 559-566.

Robinson, C. 1993. *Real world research. A resource for social scientists and practitioner researchers*. Oxford: Blackwell.

Rose, M.A. 1995. Knowledge of human immunodeficiency virus and acquired immunodeficiency syndrome, perception of risk, and behaviours among older adults. *Holistic Nursing Practice.* 10(1): 10-17.

Rounds, K.A., Galinsky, M.J., & Stevens, L.S. 1991. Linking people with AIDS in rural communities: The telephone group. *Social Work.* 36(1): 195-207.

Rossman, G.B., & Rallis, S.E. 1998. *Learning in the field*: *An introduction to qualitative research*. Thousand Oaks, CA: Sage.

Rosnow, R., & Rosenthal, R. 1996. *Beginning behavioral research: A conceptual Primer.* 2nd ed. New Jersey: Prentice-Hall.

Rosser, S. 1991. AIDS and women: *AIDS Education and Prevention*, 3(3): 230-240.

Rowe, J.W., & Kahn, R.L. 1998. *Successful aging*: *The MacArthur Foundation Study*. New York. Pantheon.

Rubin, L.B. 1976. *Worlds of pain: Life in the working-class family*. New York: Basic Books.

Russell, M., & Schneider, H. 2000. *A rapid appraisal of community based HIV/AIDS care and support programmes in South Africa*. Durban: Health Systems Trust.

Saad, K., Hartman, J., Ballard, C. et al. 1995. Coping by the carers of dementia sufferers. *Age Aging*. 24: 495-498.

SAFAIDS. 2000. HIV/AIDS and development. *HIV/AIDS Fact Sheets*, 2. Harare.

SAFAIDS. 1995. Condoms: How effective are they? *SAfAIDS News*. 3(4):14.

Sagner, A. 2000. Ageing and social policy in South Africa: Historical perspectives with particular reference to the Eastern Cape. *Journal of Southern African Studies* 26(3): 523-553.

Sagner, A., & Mtati, R.Z. 1999. Politics of pension sharing in urban South Africa. *Ageing and Society*, 19: 393-416.

Samson, M., Babson, O., MacQueen, S. et al. 2000. *The macro-economic implications of poverty-reducing income transfers*. Interim report to the Inter-ministerial Commission on Comprehensive Social Security. Johannesburg.

Sanders, D., Todd, C., & Chopra, M. 2005. Confronting Africa's health crisis: more of the same will not be enough. *British Medical Journal*. 331: 755-758.

Sapa. 2002. Nursery Schools that refused HIV child in court today. *Cape Times*, 13 June. [Online]. Available http://www.uct.ac.za/depts.cssr/seminars9. [2004, January 28]

Sapa. 2005. *Public hearings on the provincial budgets and expenditure review* 2001/02-2007/08. Presentation, Department of Social Development, Cape Town.

Sarason, B.R., Sarason, I.G., & Gurung, R.A.R. 1997. Close personal relationships and health outcomes: a key to the role of social support. *Handbook of personal relationships: Theory, research, and interventions*, 2ed. New York: John Wiley.

Sauerborn, R., Adams, A., & Hien, M. et al. 1996. Household strategies to cope with the economic costs of illness. *Social Science & Medicine*, 43(3): 291-301.

Save the Children. 2005. *Bottlenecks and drip feeds: Channeling resources to communities responding to orphans and vulnerable children in Southern Africa*. London Save the Children UK.

Schatz, E. 2007. Taking care of my own blood. Older women's relationships to their households in rural South Africa, *Scandanavian Journal of Public Health*. 33(69): 147-154.

Schatz, E., & Ogunmefun, C. 2005. *Caring and contributing: The role of older women in multigenerational households in the HIV/AIDS era*. Colorado: Institute of Behavioral Science, University of Colorado.

Schable, B., Chu, S.Y., & Diaz, T. 1996. Characteristics of women 50 years of age or older with heterosexually acquired AIDS. *American Journal of Public Health*. 86: 1616-1618.

Scheurich, J.J. 1994. Social relativism: A postmodernist epistemology for educational administration. In *Postmodern school leadership: Meeting the crisis in educational administration*. Maxcy, S.J, Ed. Westport: Praeger. 17-46.

Schoepf, B.G. 1988. Women, AIDS and economic crisis in Central Africa. *Canadian Journal of African Studies.* 22(3): 628-639.

Schoepf, B. 1991. Ethical, methodological and political issues of AIDS research in Central Africa. *Social Science & Medicine*. 33(7): 749-763.

Schultz, R., & Beach, S.R. 1999. Caregiver as a risk factor for mortality. The CaregiverHealth Effects Study. *Journal of African Medical Association.* 282: 2215-2219.

Schurink, E.M. 1998. Deciding to use a qualitative research approach. In *Research at grassroots. A primer for the caring professions*. de Vos, A.S, Ed.: Pretoria: van Schaik, 239-251.

.

Schuurmans-Stekhoven, P.M. 1992. A profile of the elderly admitted to the emergency 3 unit of Groote Schuur Hospital*:* With particular reference to their health care needs. PhD thesis. Cape Town: Department of Medicine, University of Cape Town.

Schwarz, A. n.d. Old age security. In *Age and security. How social pension can deliver effective aid to poor older people and their families*. World Bank.

Seeley, J., Kajura, C., Bachengana, M. et al. 1993. The extended family and support for people with AIDS in rural population in South West Uganda: a safety net with holes? *AIDS Care*. 5(1): 117-122.

Senegal (Republic). 2001. Senegal human rights report. Available: www.ncbay.com/refernce/country/humanrights_toc.html?code=sg [2008, February 4].

Shaik, B.T., & Hatcher, J. 2004. Health seeking behavior and health service utilization in Pakistan: challenging the policy makers. *Journal of Public Health*. 27(1): 49-54.

Shisana, O., & Davids, A. 2004. Gender and HIV/AIDS: Focus on Southern Africa. Unpublished. Pretoria: Human Sciences Research Council.

Shisana, O., Hall, E., & Maluleke, K.R. et al. 2003. *The impact of HIV/AIDS on the health sector. National Survey of Health Personnel, Ambulatory and Hospitalized Patients and Health Facilities.* Pretoria: National Department of Health.

Shisana, O., Peltzer, K., & Zungu-Dirwayi, N. et al. 2004. *The health of our educators. A focus on HIV/AIDS in South African public schools,* 2004/5 survey. Pretoria: Human Sciences Research Council.

Shisana, O., Rehle, T., & Simbayi, L. et al. 2005. *South African National HIV prevalence, HIV incidence, behavior and communication survey*. Cape Town: HSRC.

Shisana, O., Rehle, T., & Simbayi, L. et al. 2006**.** People aged 50 years and older: the neglected group in HIV surveillance and HIV prevention: Paper read in the 16th International AIDS Conference, Montreal.

Shisana, O., & Simbayi, L.C. 2002. *Nelson Mandela/HSRC Study of HIV/AIDS: South African national HIV prevalence, behavioral risk and mass media: household survey*. Cape Town: Human Sciences Research Council.

Shore, R.J., & Hayslip, B. 1994. Custodial grandparenting: Implications for children's development. In *Redefining families: Implications for children's development*. Gottfried, A., & A. Gottfried, Eds. New York: Plenum Press. 171-217.

Sidorenko, A. 2004. Implementation of the Madrid International Plan of Action on Ageing: Research dimension. *Geriatrics and Gerontology International.* 4: 87-89

Sieber, S.D. 1973. The integration of field work and survey methods. *American Journal of Sociology*, 78: 1335-359.

Siegel, K., & Gibson, M.A. 1988. Barriers to modification of sexual behaviour among heterosexuals at risk for acquired immunodeficiency syndrome. *New York State Journal of Medicine,* 2: 66-70.

Siegel, K., Bradley, C.J., & Lekas, H.L. 2004. Causal attributions for fatigue among late middle-aged and older adults with HIV infection. *Journal of Pain and Symptom Management.* 28(3): 211-224.

Silverman, D. 1993. *Interpreting qualitative data*. London: Sage.

Simbayi, L.C., Kleintjies, S., & Ngomane, T. et al. 2006. *Psychosocial issues affecting orphaned and vulnerable children in two South African communities.* Cape Town: Human Sciences Research Council.

Skeldon, R. 1999. *Ageing of rural populations in South-East and East Asia*. Rome: Sustainable Development Department, FOA.

Skweyiya, Z. 2007. Social Development Department Budget Vote. Budget vote speech to the National Council of Provinces in Cape Town. Available: http//www.polity.org.za/article.php?a_id [2007, December 26].

Smart, R. 1999. *AIDS brief for professionals: health care workers.* Durban: Health Economics and HIV/AIDS Research Division (HEARD). University of KwaZulu- Natal.

Smart, R. 2000. *Children living with HIV/AIDS in South Africa*: *A rapid appraisal*. Pretoria: National AIDS Care and Support Task Team **(**NACCT).

Smith, S. 2001. ILO's response to HIV/AIDS in the world of work. *Sexual Health Exchange.* 4: 3-4.

Smith, D. 2002. Hospital stands firm on sacked Von Mollendorf. *Saturday Star*, Available: http://www.iol.co.za [2007 December 18].

SPSS Incorporated. 2006. *Statistical package for the social sciences* (Version 15.0). Chicago, IL: SPSS Incorporated.

Sogaula**,** N., Van Niekerk, R., & Noble, M. et al. 2002. *Social security transfers, poverty and chronic illness in the Eastern Cape: An investigation of the relationship between social security grants the alienation of rural poverty and chronic illness* (*including those associated with HIV/AIDS*). *A case study of Mount Frere in the Eastern Cape*. Cape Town: Duke University Press.

South African (Consulate). n.d. Moving South Africa Strategy. Department of Transport report. Available: www.southafrica-newyork.net/consulate/transport.htm). [2008, May 12].

South African participatory poverty assessment (SA-PPA). 1997. The experience and Perceptions of poverty: Durban: Praxis.

South African Medical Research Council (MRC). 2006. 336, 000 South Africans died from AIDS in one year. Parliament, August, Sapa.

South Africa (Republic), Department of Education. *Adult Basic Education and Training* Act. (Act 52 of 2000). Pretoria.

South Africa (Republic), Department of Health. 2002. Free State provincial home based care policy. Bloemfontein: DoH.

South Africa (Republic), Department of Health report. 2002. Reflection on a decade of Health report. Available: http://www.health-e.org.za/news/article.php? [2007, December 17].

South Africa (Republic), Department of Health. 2003. Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa. Pretoria: DoH.

South Africa (Republic), Department of Health. 2000-2005. *HIV/AIDS/TB Strategic Plan for South Africa*. Pretoria: DoH.

South Africa (Republic), Department of Health. 2007-2011. *HIV /AIDS and STI: National Strategic Plan*. Pretoria: DoH.

South Africa (Republic), Department of Social Development. 2002. National Report on the Status of Older Persons. 2002. Report to the Second World Assembly on Ageing, Madrid, Spain. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. n.d. South African policy for older persons. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. *Strategic Plan, 2006/7-2009/10 for South Africa*. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. 1994-2002. *National report on the status of older persons. Report to the second World Assembly on Ageing*. Madrid, Spain: Pretoria.

South Africa (Republic), Department of housing. n.d. A new housing policy and strategy for South Africa. White paper. Pretoria: Department of Housing.

South Africa (Republic). 1996. *Constitution of the Republic of South Africa* (Act 108 of 1996). Available: http://www.info.gov.za/documents/constitution/index.htm [2007, December 28].

South Africa (Republic). 2003. *National Health Act* (Act 61 of 2003). Available: http://www.info.gov.za/gazette/acts/2003/a61-03.pdf [2007, December 28].

South Africa HIV/AIDS Operational Plan. 2003. *An operational plan for comprehensive HIV and AIDS care, management and treatment.* Pretoria: Department of Health.

South Africa (Union). 1939. Verbatim report of the proceedings of the Native Representative Council (NRC) (mimeographed, 1940). 495-497.

South African Institute of Race Relations. 1999. *South Africa survey*. Millennium edition. Johannesburg: SAIRR.

Standing, H., & Kisekka, M. 1989. *Sexual behaviour in Sub-Saharan Africa – a review and annotated bibliography*. London: Overseas Development Administration.

Statistics South Africa (StatsSA). 2006. General household survey. Pretoria. Available: www.sair.org.za/research-and-publications/th... [2009, October 29].

Statistics South Africa (StatsSA). 2007. Community Survey: Basic results. Pretoria. Available: www.statssa.gov.za/publications/CS2007Basic/CS2007Basic.pdf [2009, September 13].

Statistics South African (Stats SA). 2008. Mid-year population estimates. Available: www.statssa.gov.za [2008, October 15].

Southern African Network of AIDS Service Organizations (SANASO). 2001. Focus on Swaziland. SANASO *Newsletter*. 38: 3-6.

Spotnitz, R. 1997. Planning for the future-continued care of the adult dependent child after the elderly parent-caregiver's death: An exploratory study of the process by which aging parents prepare for the transition of care. PhD thesis. Long Beach, CA: Department of Social Work, University of California.

Stakes, R.E. 1981. Case study methodology: An epistemological advocacy. In *Case study methodology in education evaluation*. Welch, W.W., Ed. Minneapolis: University of Minnesota, Research and Evaluation Center. 31-40.

Stakes, R.E. 1995. *The art of case study research*. Thousand Oaks, CA: Sage.

Statistics South Africa. 2001. *Achieving a better life for all. Progress between Census* '96 *and 2001* Report. Pretoria: Stats SA.

Steinberg, M., Johnson, S., Schierhout, M. et al. 2002. *Hitting home: how households cope with the impact of the HIV/AIDS epidemic*. Cape Town: Henry J. Keiser Foundation and Health Systems Trust.

Stephenson, R., & Hennink, M. (2004). Barriers to family planning service use among urban poor Pakistan. *Asia Pacific Popuationl Journal.* 19: 5-26.

Stewart, D., & Shamdasani, P. 1990. Focus groups: theory and practice. *Applied Social Science Research Methods Series*, 20. Newbury Park: Sage.

Stloukal, L. 2001. Rural population ageing in poorer countries: Possible implications for rural development. *Journal of the International Institute on Ageing.* 11(4): 16-23.

Stover, J., Walker, N., & Garnett, G.P. 2002. Can we reverse the HIV/AIDS pandemic with an expanded response? *Lancet.* 360: 73-77.

Strauss, A. 1987. *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.

Strauss, A. & Corbin, J. 1998. *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2ed.). London: Sage.

Strydom, H. 2000. The knowledge base of high school pupils in the North West province on HIV/AIDS in Southern Africa. *American Journal of Public Health*, 90(7): 1042-1048.

Sundar, T.R.S., & Varghese, T. 2003. *Study report on older people and child care*.Tamil Naidu, India: International HIV/AIDS Alliance.

Swan, N. 2001. *AIDS in South Africa: Health minutes.* Available: http://www.abc.net.au/health/minutes/stories [2007, November 20].

Swart, D., Joubert, J.D., & Reddy, P. 1998. *Knowledge, perceptions and needs of older persons with reference to 1999, the International Year of Older Persons*: A qualitative study in the Western Cape. Unpublished. Parow Valley: SA Medical Research Council.

Swaziland National Strategic Plan for HIV/AIDS. 2000-2005. Prepared by the HIV/AIDS Crisis Management and Technical Committee. September 2000.

Swaziland Demographic and Health Survey (SDH) CSO. 2008**.** The 2nd National Multisectoral HIV/AIDS Strategic Plan 2006 – 2008. Available: http://www.popline.org/docs/1798/327506.html [11, June 2008].

Szirony, T.A 1999. Infection with HIV in the elderly population. Toledo: Medical College of Ohio, School of Nursing,

Takumura, J., & Williams, B. n.d. *Informal caregiving. Compassion in action: An introductory message*. Available: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2003-respite-releve/2003-respite-releve_e.pdf [2007, February 3].

Tashakori, A., & Teddlie, C. 1998. *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Thibaut, J.W., & Kelly, H.H. 1959. *The Social Psychology of groups*. New York: John Wiley.

Tawfik, L., & Kinoti, S. 2001. *The impact of HIV/AIDS on the health sector sub-Saharan Africa: the issue of human resources*. Pretoria: Support for Analysis and Research in Africa Project USAID, Bureau for Africa, Office for Sustainable Development.

Taylor, L., Seeley, & Kajura, E. 1996. Informal care for illness in rural southwest Uganda: the central role that women play. *Health Transition Review*. 6(1): 49-56.

Tewodros, A. 2004. Forgotten families: Support older carers of orphans and vulnerable children. Presentation in the Orphans and Vulnerable Children. (OVC-TG) workshop, Washington D.C.: The World Bank, March 18.

Tewodros, A., & Nhongo, T.M. 2006. Innovative programmes that address the impact of HIV/AIDS on older people in sub-Saharan Africa. *Global Ageing: Issues and Action*. 33-44.

Therkildsen, O., & Semboja, J.A. 1995. New look at service provision in East Africa. Semboja, J., & O. Therkildse, Eds. In *Service provision under stress in East Africa*: *The state, NGOs & people's organisations in Kenya, Tanzania and Uganda*. Copenhagen: Centre for Development Research. 1-34.

Thomas, A. 1998. Challenging cases. In *Investigative skills for policy and development: Finding out fast*. Thomas, A., J. Chataway, & M. Wuyts, Eds. London: Sage.

Thomson, R., & Scott, S. 1990. *Researching sexuality in the light of AIDS*: *historical and methodological issues.* Women, Risk & AIDS Project, Paper 5. London: Tufnell Press.

Timaeus, I., & Jassen, M. 2003. *Adult mortality in sub-Saharan Africa: evidence from the demographic and health surveys*. Paper presented in the Conference on Empirical Evidence for the Demographic and Socio-Economic Impact of AIDS. Durban, March 26-28.

Tlou, S. 1996. Empowering older women in AIDS prevention: The case of Botswana. *Southern African Journal of Gerontology*. 5(2): 1-36.

Toms, I. 1990. AIDS in South Africa: potential decimation on the eve of liberation. *Progress Reports on Health & Development in Southern Africa*. 13-16.

Tribe, M.A. 1976. *Social security in Africa: Trends, problems and prospects. African Affairs.* 75: 410-411.

Troisi, J. 2004. *Ageing in Africa: Older persons as a resource.* Paper presented in the African Conference on Ageing, Johannesburg, August, 18-20.

Udjo, E. O. 2006. Demographic impact of HIV/AIDS on the young and elderly populations in South Africa. *Journal of Intergenerational Relationships.* 4: 23-41.

Udjo, E. n.d. *Additional evidence regarding fertility and mortality trends in South Africa and implication for population projections*. Pretoria: Statistics South Africa.

Uganda (Republic), Ministry of Health. Policies and programmes. Available: http://www.health.go.ug. [2007, December 26].

Uganda Commission on Human and Peoples' Rights. 2006. Report to the Commission on human and people's rights, presented in the 39th ordinary session of the Commission on Human and Peoples' Rights Banjul, Gambia.

Uma, N. 1997. *Dislocating cultures, identities, traditions and third world feminism*. New York: Routledge.

UNICEF. 2004. A joint report of new orphan estimates and a framework for action. New York: UNICEF.

UNAIDS. 1997. *Community mobilization and AIDS*. UNAIDS Technical update report. UNAIDS Best practice collection. Geneva: UNAIDS.

UNAIDS. 1998a. *HIV/AIDS and the workplace: Forging innovative business responses.* UNAIDS Technical Update. Best Practice Collection. Geneva: UNAIDS

UNAIDS. 1998b. *HIV-related opportunistic diseases*. Technical Update. Geneva: UNAIDS

UNAIDS. 1999. *Handbook for legislators on HIV/AIDS, law and human rights: Action to combat HIV/AIDS in view of its devastating human, economic and social impact.* Geneva: UNAIDS.

UNAIDS. 2000a. *HIV and AIDS related stigmatization, discrimination and denial: Forms, contexts and determinants. Research studies from Uganda and India. Key materials*. Geneva: UNAIDS.

UNAIDS. 2000b. *Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa*. UNAIDS Best Practice collection. Available: www.whglibdoc.who.int/unaids/2000/UNAIDS_00.29E.pdf [2008, December 11].

UNAIDS. 2000c. *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

UNAIDS. 2000d. Best practice digest. In *Current issues in HIV counseling and testing in South and Southeast Asia*. A report of a workshop held in Mumbai, India, February 1999.

UNAIDS. 2001. *Advocacy for action on stigma and HIV/AIDS in Africa.* Regional Consultation Meeting on Stigma and HIV/AIDS in Africa. Dar-Es-Salaam, Tanzania, June 4-6.

UNAIDS. 2002. *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

UNAIDS. 2003. *AIDS Epidemic Updates*. Geneva: UNAIDS.

UNAIDS. 2004a. *Report on the global AIDS epidemic*: *Fourth Global Report.* Geneva. UNAIDS.

UNAIDS. 2004b. *Coverage of selected services for HIV/AIDS prevention and care in low and middle-income countries in* 2003. Policy project. Global AIDS report. Geneva: UNAIDS.

UNAIDS. 2006. *Report on the global AIDS epidemic. Executive summary*. A UNAIDS 10th anniversary special edition. Geneva: UNAIDS.

UNAIDS. 2007. *AIDS epidemic update*: *December 2007-2008*. Geneva: UNAIDS and WHO.

UNAIDS. 2008. Report on the global AIDS epidemic. Available: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp [2008, December 25].

UNAIDS/UNICEF/USAID. 2002. *A joint report on orphans, estimates and program strategies*. Geneva: UNAIDS.

UNAIDS /WHO. 2001. *AIDS epidemic update*. Geneva: UNAIDS & WHO.

UNAIDS/WHO. 2005. *"3 by 5" Progress Report, December 2004*. Available: http://www.who.int/3by5/progressreport05/en/ [2007, August 20].

United Nations. 1948. *Universal Declaration of Human Rights*. Available: http://www.un.org/Overview/rights.html [2006, June 30].

United Nations. 1991. *United Nations Principles for Older Persons*. Principles adopted by the General Assembly for Older Persons. Resolution 46/91. New York: UN. Available: www.un.org/esa/socdev/ageing/ageipaa.htm [2007, May 10].

United Nations. 1993. *Vienna Declaration and Programme of Action*. World Conference on Human Rights. Resolution A/CONF.157/23. Available: http://www.unhchr.ch/huridocda/huridoca.nsf/(Symbol)/A.CONF.157.23.En [2007, October 30].

United Nations. 1998. *HIV/AIDS and human rights: International guidelines*. Second International Consultation on HIV/AIDS and Human Rights. Geneva, September, 24.

United Nations. 1999. *Human rights and older persons*. Compendium of extracts from the General Comment No. 6, adopted by the Committee on Economic, Social and Cultural Rights in 1995. Geneva.

United Nations. 2000. *Millennium Declaration*. Resolution adopted by the General Assembly. New York: UN.

United Nations. 2001a. *Declaration of Commitment on HIV/AIDS*. General Assembly Special Session (UNGASS) on HIV and AIDS. A/Res/S-26/2. New York: UNGASS.

United Nations. 2001b. *World population prospects. The 2000 revision: Highlights*. New York: Population Division, Department of Economic and Social Affairs.

United Nations. 2002a. *Millennium Development Goals.* Available: www.un.org/milliniumgoals/ [2005, August 23].

United Nations. 2002b. *Madrid International Plan of Action on Ageing*. New York: UN. Available: www.un.org/esa/socdev/ageing/waa/a-conf-197-9b.htm. [2006, November 30].

United Nations. 2004a. *Facing the future together*. Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa. Geneva: UNAIDS.

United Nations. 2004b. *Policy framework on HIV/AIDS*. New York: UN.

United Nations. 2004c. *Follow up to the International Year of Older Persons: Second World Assembly on Ageing*. Report of the Secretary General (A/59/164). New York: UN.

United Nations. 2005. *2005 World Summit outcome*. Resolution adopted by the General Assembly. New York: UN. (A/RES/60/1).

United Nations**.** 2006. *The Millennium Development Goals Report*. New York: UN. Available: www.un.org/milleniumgoals/ [2006, November 23].

United Nations. 2007a. *World population ageing*. New York: UN Economic and Social Affairs, Population Division.

United Nations. 2007b. *World population monitoring, focusing on the changing age structures of populations and their implications for development*. Report of the Secretary-General. New York: UN.

United Nations/ Help the Aged(UN/HtA). 2005. *Valletta Declaration*. Commonwealth Heads of Government meeting, Expert workshop on HIV and AIDS and Older People. Valletta, Malta.

United Nations International Children's Fund and World Health Organization. 1978. Primary Health Care. Report of the International Conference on Primary Health Care. Geneva.: World Health Organization.

United Nations Population Development (UNDP). 1991. Human Development Report, 35-36. New York: UNDP.

United Nations Population Development (UNDP). 1998. *Human Development Report in Lesotho*. Maseru: UNDP.

United Nations Population Development (UNDP). 2001. *HIV/AIDS: Implications for poverty reduction*. New York: UNDP.

United Nations Development Programme (UNDP). 2003. *Disease, HIV/AIDS and capacity implication*: a case of the public education sector in Zambia. Research Paper 2. New York: UNDP.

United Nations Population Development (UNDP). 2006. *Botswana Human Development Index*. UNDP, Human Development Report.

United Nations Development Programme (UNDP). 2007. *Making globalization work for all*. United Nations Development Programme Annual Report. New York. Available: www.undp.org/publications/annualreport2007/IAR07-ENG.pdf [2008, November 26].

United Nations Development Programme (UNDP). 1992. *Young women: silence, susceptibility and HIV infection. Age and gender as independent variables in the acquisition of HIV*. New York: UNDP.

UNESCO. 2000. *The Dakar framework for action, education for all: meeting our collective commitments*. World Education Forum. Dakar, Senegal. April, 26-28.

UNESCO. 2002. EFA global monitoring report, 2002: is the world on track? Paris: UNESCO. Available: ww.unesco.org/education/efa/monitoring/monitoring_2002.shtml. [2007, October 22].

UNICEF. 1984. Overview of evaluation activities in UNICEF. Unpublished. New York: UNICEF.

UNICEF/UNAIDS. 1999. *Children orphaned by AIDS. Frontline responses from eastern and southern Africa*. New York: UNICEF division of communication.

UNICEF. 2001. *The state of the world's children 2001*. New York: UNICEF

UNICEF. 2003. *Africa's orphaned generations*. Annual Report. New York: UNICEF.

United Nations Population Fund **(**UNFPA). 2004. *Integrating HIV voluntary counseling and testing services into reproductive health setting. Stepwise guidelines for programme planners, managers and service providers*. New York: UNFPA.

United Nations Population Fund **(**UNFPA). 2002a. *Population ageing and development*. Operational challenges in developing countries. New York: UNFPA.

United Nations Population Fund **(**UNFPA). 2001. *Preventing infection, promoting reproductive health. UNFPA's Response to HIV/AIDS*, New York: UNFPA.

United Nations Population Fund (UNFPA). 2002b. *Situation and voices. The older poor and excluded in South Africa and India*. Technical Support Division: New York: UNFPA.

Urassa, M., Ties Boerman, J., Ng'weshemi, J. et al., 1997. Orphanhood, child fostering and the AIDS epidemic in rural Tanzania. *Health Transition Review*. 2(7): 141-153.

United Agency for International Development (USAID). 1996. *Performance monitoring and evaluation. conducting key informant interviews.* Center for Development Information and Evaluation. TIPS, 2. Arlington: USAID.

United Agency for International Development (USAID). 2002. *HIV/AIDS prevention, care and support across faith-based communities: An annotated bibliography of resources*. HRN-A-00-97-0017-00. Arlington, VA: USAID.

United States Census Bureau (USCB). 1998. *Focusing on HIV/AIDS in the developing world. World population profile*. Report WP/98. Washington, DC: USCB

United States Census Bureau (USCB). 2005. *International database*. Washington D.C.: USCB.

United States Presidential Emergency Plan for AIDS Relief (PEPFAR). 2008. *Pepfar operational plan*, June 2008. Available: http://www.pepfar.gov/documents/organization/107838 [2008, November 22].

Uys, L. 2003. Longer-term aid to combat AIDS. Editorial. *Journal of Advanced Nursing*. 44(1): 1-2.

Valdes, B., & Henriques, J. 1983. Health status of the Cuban people. *International Journal of Health Services.* 13: 479-86.

Valenti, W.M. 1995. Infection control, human immunodeficiency virus, and home health care: Risk to the caregiver. *American Journal of Infection Control.* 23(2): 78-81.

Valsiner, J. 1986. *The individual subject and scientific psychology*. New York: Plenum.

Van der Geest, S. 1997. Between respect and reciprocity: managing old age in rural Ghana. *Southern African Journal of Gerontology*. 6(2): 20-25.

Van Praag, E. n.d. Continuum of care and support: HIV/AIDS prevention. Arlington, VA: Care Department, Family Health International.

Vapi, X. 2004. Grants help destitute spring the poverty trap. Far from creating dependency, social grants raise the odds of finding work. *Cape Argus*, December 12. p 6.

Walt, G. 1994. *Health policy: An introduction to process and power. People, government and international agencies – who drives policy and how it is made*. Johannesburg: Witwatersrand University Press.

Webb, D. 1997. The sexual and economic politics of (re) integration: HIV/AIDS and the question of stability in Southern Africa. *SAfAIDS News.* 5(4): 2-6.

Weidlich, B. 2007. Gays and lesbians left out of AIDS policy. *The Namibian*, 26 March. 3.

Weiss, H.A., Quigley, M.A., & Hayes, R.J. 2000. Male circumcision and risk of HIV infection in sub-Saharan Africa: a systematic review and meta-analysis. *AIDS 2000.* 14(15): 2361-2370.

Welman, J.C., & Kruger, S.J. 2002. *Research methodology for business and administration science*. 2nd ed. Oxford: Oxford University Press.

White, H. 2002. Combining quantitative and qualitative approaches in poverty Analysis. *World Development.* 30(3): 511-522.

Whiteside, A., & Suntner, C. 2000. AIDS: *The challenge for South Africa*. Cape Town: Human & Rousseau, and Tafelberg.

Williams, A. 2003. *Ageing and poverty in Africa: Ugandan livelihoods in a time of HIV/AIDS*. Hampshire: Ashgate.

William, G., & Tamale, N. 1991. *The caring community: Coping with AIDS in urban Uganda*. Action Aid, London African Medical & Research Foundation. Nairobi: AMREF.

Wilson, D. 2000. *Issues in home care in Southern Africa*, presentation to Regional Norwegian-Swedish HIV/AIDS Meeting: Strengthening integration of HIV/AIDS into Development Cooperation, 16-17 November, Zombe, Malawi.

Woelk, G., Jackson, H., Kerkhoven, R. 1997. *Do we care? The cost and quality of community home based care for HIV/AIDS patients and their communities in Zimbabwe*, Harare: University of Zimbabwe, SAfAIDS and , Ministry of Health and Child Welfare.

Wolcott, H.T. 1994. *Transforming quantitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage.

Wooten-Bielski, K. 1999. HIV and AIDS in older adults. *Geriatric Nursing*. 20(5): 268-272.

World Bank. 1993. *Uganda: Growing out of poverty – a World Bank country study*, International Bank for reconstruction and development (IBRD), Washington D.C.

World Bank. 2006. *Grandmothers promote maternal and child health*: *the role of* i*ndigenous knowledge systems managers*. Available: www.worldbank.org/afr/ik/iknt89.ht [2006, June 23].

World Health Organization. 1978. *Primary Health Care, Report of the International Conference on Primary Care*, Alma Ata. Geneva: WHO.

World Health Organization. 1996. *Integration of health care delivery. Report of WHO study group*. WHO Technical Report Series No. 861. Geneva: WHO.

World Health Organization. 2000. *Active ageing: A policy framework*. Geneva: WHO.

World Health Organization. 2001. *Information needs for research, policy and action on ageing and older persons, definition of an older or elderly person*. WHO Statistical Information system. Available: http://www3.who.int/whosis/mds/mds_definition [2005, October 23].

World Health Organization. 2002a. *The impact of AIDS on older people in Africa*: *Zimbabwe case study*. Geneva: WHO.

World Health Organization. 2002b. *Guidelines on Care and Support in Resource Limited Settings.* Geneva: WHO.

World Health Organization. 2002c. *Policy Framework for Community Home Based Care in Resource Limited Settings*. Geneva: WHO

World Health Organization. 2003. Report on the review of Primary Health Care in the African region. Brazzabille: WHO, Regional Office for Africa.

World Health Organization. 2004a. *Active ageing:* Towards age-friendly Primary Health Care. *Active Ageing Series*. Geneva: WHO.

World Health Organization. 2004b. *Changing history*. World Health Report. Geneva: WHO.

World Health Organization. 2004c. *Health sector reform and district health systems. District management team training module*. Brazzaville: WHO Regional Office for Africa.

World Health Organization. 2005. *Health action in crisis, Lesotho*. Geneva: WHO.

World Health Organization. 2006. *Taking stock: Health worker shortages and the response to AIDS*. World Health Report. Geneva: WHO.

World Health Organization. n.d. *STDs case management: A guide to syndromic management.* Geneva: WHO.

WHO/UNICEF/Government of Mali. 1999. Report on the review of the implementation of the Bamako Initiative in Africa. Bamako, Mali, March 8-12.

Yamagishi, T. 1987. An exchange theoretical approach to network positions. *In Social exchange theory*. Cook, K.S. Ed. London: Sage.

Yin, R.K. 1989. *Case study research: Design and methods*. Newbury Park, CA: Sage.

Yin, R.K. 1994. *Case study research: Design and methods*. 2nd ed. Applied Social Research Methods Series. Vol 5. Thousand Oaks, CA: Sage.

Zejly, A., & Galibaka, G. 2005-2009. *Country strategic paper. Republic of Senegal*, 2005-2009 *report*. Senegal.

Zelenetz, P.D., & Epstein, M.E. 1998. *HIV in the elderly - AIDS Patient Care STDS*. New York: Department of Medicine, North Shore University Hospital.

Zierler, S., Cunningham, W.E, & Andersen, R. et al. 2000. Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *Journal of Public Health*. 90(2): 208-215.

Zwarenstein, M., & Barron, P. 1992. *Managing Primary Health Care in South Africa at the district level.* The Medical Research Council/Institute for Urban Primary Health Care Workshop. Health Systems Division of the Centre for Epidemiological Research in South Africa. Parow Valley: SA Medical Research Council.

ANNEXURE 1

THE RESPONDENTS' INFORMED CONSENT FORM

Good morning/afternoon

My name is……I am part of a group of people working on a 3 province study on the role and support needs of older persons caring for their children living with HIV and AIDS and their grandchildren. This study has been funded by the Nelson Mandela Foundation and is facilitated by the Human Sciences Research Council (HSRC). The results of this study will help to understand the role played by the older persons in the prevention and management of this disease in South Africa. Furthermore, it will assist in the planning of support programmes for older caregivers.

I would like to ask you some questions about your household. Some of the questions may be sensitive. If you agree to participate in this study, you will remain anonymous: your name will not be used in any publication and the information you give will be kept confidential. Your household was selected to participate in this study. Your frank and honest responses will help us reach the aims of this study.

If you are willing to participate in the study, please sign your name below. If you have any questions or queries at anytime, please feel free to contact Mr……. at telephone number(s) (021) 406 6940 (w) or 083 987 0391.

I agree to participate in this study.

Name: _____

Signature: _____ Date: (dd/mm/yy) __/____/_____

Witness: _____

I am not willing to participate in this study.

Age:……

Gender:……

Race:……

Province:……

ANNEXURE 2

THE SURVEY QUESTIONNAIRE

IDENTIFICATION DATA

Interviewer's name:…… Preferred Language of respondent……

Data Collection Form No: | | | | | |

Date: (dd/mm/yy) / /

Geographical Area:

Urban	Non urban	Province
1	2	

Type of dwelling :

Brick house	Mud house	Shack	Other(specify…
1	2	3	4

INCOMPLETE INTERVIEW LOG:

	Visit 1	Visit 2	Visit 3
Time			
Comment			

Comment codes : Interview completed (1), Appointment made for another day 2

Refused to participate (3), Can't complete interview (4),
Other 5 (Specify**:……**

Interviewer starting time:

Stopping time:

SECTION 1

DEMOGRAPHY

1. Older Person's Biographical Data

1.1. In what year were you born?

1.2. Sex: Male……1
Female……2

1.3. Language: (**as identified by respondent**)

isiXhosa	isiZulu	Sotho	English	Afrikaans	Other
1	2	3	4	5	6

1.4. What is your nationality?:

South African	1
Other: Specify……	2

1.5. What is your marital status?:

a. Married	1
b. Widowed	2
c. Separated	3
d. Divorced	4
e. Never married	5

1.6. From which of the following sources do you derive income (**respondent's only**)?

	Yes	**No**
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2

1.7. What is the highest standard you completed at school? **(tick one option only)**

a. No schooling	1
b. Sub A	2
c. Sub B	3
d. Standard 1	4
e. Standard 2	5
f. Standard 3	6
g. Standard 4	7
h. Standard 5	8
i. Standard 6	9
j. Standard 7	10
k. Standard 8	11
l. Standard 9	12
j.Standard 10	13
m. Other: specify……	14

HOUSEHOLD INFORMATION

I am now going to ask you about all the people who live in this household? I only need to know their first names, gender, age and relationship to you.

Interviewer: Complete the grid below for all persons who live in the household. Probe, to check that all co-residents have been mentioned.

Definition of "live in this household": All persons who live in the household (i) at least four months of the year, and (ii) eat from a common pot when they are here.

Person Code	First Name	Gender M or F	Age (years)	Relationship to respondent	Attend school=1 Don't attend= 2 N/A. = 3	Working/employed (earning weekly/monthly salary) Yes =1; No=2; N/A = 3
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						

Gender code: 1= male 2 = female

Relationship to respondent Code: 1= Head of household
2 = spouse, partner
3 = son,
4 = daughter
5 = Grandchild
6 = Mother/father in-law
7 = Son/daughter in-law
8 = Brother/sister in-law
9 = Aunt, uncle
10 = Niece, nephew
11 = Sister, brother
12 = other relative
13 = lodger
14 = Household helper
15 = Father, mother

1.8. Are you the head of this household? | Yes=1 | No=2 |

1.9. How long have you lived in this township/village (in years)?

1. Less than 1year	1
2. 1 =< 2 years	2
3. 2 =< 5 years	3
4. 5 =< 10 years	4
5. >= 10 years	5

1.10. How long have you lived in this house?

1. Less than 1year	1
2. 1 =< 2 year	2
3. 2 =< 5 years	3
4. 5 =< 10 years	4
5. > =10 years	5

1.11. Where does this household get water? **(more than one answer possible)**

	Yes	No
1. From a river/water stream/pond	1	2
2. Tap (inside house)	1	2
3. Tap (in the yard)	1	2
3. Communal tap	1	2
4. Other (Specify……		3

1.12 What type of toilet facility does this dwelling have?

a. Flush toilet inside house.	1
b. Flush toilet in yard.	2
c. Communal flush toilet	3
d. Pit latrine	4
e. Bucket toilet	5
f. Chemical toilet	6
g. No toilet/Not available	7
h. Other (Specify….	8

1.13. Which forms of energy are used in this house? (**more than one answer possible**)

	Yes	**No**
1. Timber/wood	1	2
2. Electricity	1	2
3. Coal/anthracite	1	2
4. Paraffin	1	2
5. Gas	1	2
6. Other (Specify……		3

1.14. I am going to read you a number of statements. Which one best describes your household situation?

	Yes	**No**
1. Not enough money for basic things like food and clothes		
2. Have enough money for food and clothes, but short on many other things		
3. We have a radio		
4. We have a TV		
5. We have a refrigerator		
6. We have a car		

1.15. How many rooms does this house have ? **(including kitchen but excluding bathroom/toilet)**

1. One room	1
2. Two rooms	2
3. Three rooms	3
4. > Three rooms	4

1.16. From which of the following sources does this household derive its income? **(more than one answer possible)**

	Yes	**No**
1. Government child support grant	1	2
2. Social old age Pension	1	2
3. Employer Pension	1	2
4. Remmittance from family member(s)	1	2
5. Employed (full-time)	1	2
6. Employed (part time/odd jobs)	1	2
7. Self employed (e.g. hawking)	1	2
8. Donation by private welfare organisation(s) (e.g. church)	1	2
9. No income	1	2
10. Other (Specify…		

1.17. From which of the following sources do you personally derive income? **(more than one answer possible)**

	Respondent	**Household**
1. Child support grant	1	2
2. Social old age Pension	1	2
3. Employer Pension	1	2
4. Foster care grant	1	2
5. Care dependency grant	1	2
6. Child disability grant	1	2
7. Unemployment insurance	1	2
8. Workmen's compensation	1	2
9. Remmittance from family member(s)	1	2
10. Employed (full-time)	1	2
11. Employed (part time/odd jobs)	1	2
12. Self employed (e.g. hawking)	1	2
13. Donation by private welfare organisation(s) (e.g. church)	1	2
14. No income	1	2

1.18. If you do not derive any income from government, what is the reason(s) for this?

(do not read options)

	Yes	**No**	**Not applicable**
1.Don't know where to apply	1	2	3
2. Government offices too far (in Town)	1	2	3
3. Don't have legal papers (e.g. birth certificate; child clinic card ID book)	1	2	3
4. Not eligible	1	2	3
4. Other (Specify…….			

1.19. I am going to read you a number of statements. Which one best describes your household's financial situation? **(Interviewer read the options to respondent)**

1. Have enough for basic necessities	1
2. Sometimes don't have enough for basic necessities	2
3. Often unable to buy basic necessities	3
4. Have to borrow money to survive	4

SECTION 2

I am now going to ask you about your health and well-being

1.20. How would you rate your health at present?
(**read out the options loud)**

1	2	3	4
Excellent	Good	Fair	Poor

1.21. Compared to people of your age, would you say your health is "better", the "same" or "worse" than theirs?

1	2	3
Better	Same	Worse

1.22. Which of the following health conditions do you have at present? Is the condition being treated at a clinic or by a doctor?

Health condition

	Yes, not being treated	Yes, being treated	No	Not sure
1. Stress	1	2	3	4
2. Depression	1	2	3	4
3. Hypertension (high blood pressure)	1	2	3	4
4. Arthritis or rheumatism	1	2	3	4
5. Diabetes	1	2	3	4
6. Eye sight problem	1	2	3	4
7. Hearing problem	1	2	3	4

8. Heart condition	1	2	3	4
9. Stroke	1	2	3	4
10. TB (Tuberculosis)	1	2	3	4
11. Cancer	1	2	3	4
12. Asthma	1	2	3	4
13. Epilepsy (convulsions or fits)	1	2	3	4
14. Stomach ulcer(s)	1	2	3	4
15. Loss of memory	1	2	3	4
16. Kidney problem	1	2	3	4
17. Shortness of breath	1	2	3	4

SECTION 3

HIV/AIDS KNOWLEDGE AND AWARENESS

I am now going to ask you questions about HIV/AIDS

1.23. Do you know what HIV/AIDS is?

Yes	No
1	2

(If No, go to 1.30; if yes, go to1.24)

1.24. I am going to read you a list of statements about AIDS. Please tell me whether you Agree, Disagree or are Not sure with the statement in each case. **(interviewer read options to respondent)**

AIDS is…	**Agree**	**Disagree**	**Not sure**
1.A disease caused by a germ(virus)	1	2	3
2.A disease caused by witchcraft	1	2	3
3.A disease caused by poor nutrition	1	2	3
4. Punishment from God	1	2	3
5.Other (please specify…….	1	2	3

1.25. Where did you get your knowledge about HIV/AIDS ? **(read options, multiple responses possible)**

	Yes	***No***
1. From the TV	1	2
2. From Radio	1	2
3. In Newspapers	1	2
4. In pamphlets/ Magazines.	1	2
5. From Doctor/nurse	1	2
6. Other (Specify…..		

1.26. Do you understand the information given about HIV/AIDS?

Yes	No	Not sure
1	2	3

1.27. In your opinion is it possible to transmit HIV by means of the following?
(read the options loud)

	Yes	No	Don't Know
1.Kissing	1	2	3
2.Sitting on a toilet seat	1	2	3
3.Touching someone with HIV/AIDS	1	2	3
4.Drinking from the same mug	1	2	3
5.Breathing the same air as an HIV+ person	1	2	3
6.Exchanging bodily fluids	1	2	3
7.Unprotected sex	1	2	3
8. Other(specify…….			

1.28. Can older persons be infected with HIV?

Yes	No	Not sure
1	2	3

(If No go to 1.30; If not sure, go to 1.30; if yes go to 1.29)

1.29. How can older persons protect themselves from being infected with HIV? **(Do not prompt)**

	Yes	No	Don't know
1.Wear protective gloves when cleaning clothes and washing a sick person with AIDS	1	2	3
2. Use a condom if sexually active	1	2	3
3. Drinking traditional herbs (muti)	1	2	3

SECTION 4

I am going to ask you about your caregiving to an adult person(s)in this household (someone who is 18-49 years old). **By caregiving I mean**: cooking, feeding, washing, providing medication, taking the sick person to a doctor/clinic or hospital because the person is unable to do these tasks him/herself.

1.30. Are you presently caring for a young adult in this household (between 18 and 49 years) who has been sick for a long time?

Yes	No
1	2

(If No, go to 1.44 ; if yes,go to 1.31)

1.31. Are you presently caring for an adult family member(s) who is (are) has AIDS - who is either living in this house or elsewhere?

Yes	No
1	2

1.32. Is there someone who helps you with daily caregiving to the sick person(s) with HIV/AIDS?

Yes	No
1	2

(if No, go to 1.35; if yes go to 1.33)

1.33. If Yes, who is this person(s)?

	Yes	No
1. My husband/partner	1	2
2. My other child(ren)	1	2
3. My grandchild(ren)	1	2
4. NGO/CBOs (counselors; home carers; home visitors)	1	2
5. Community nurse(s)	1	2
6. Nurse Aid	1	2
7. Neighbour(s)	1	2
8. Other relative	1	2
9. Friends	1	2
10. Other (Specify…		3

1.34. What type of help or support does this/these person(s) provide?

(more than one answer accepted)

Support provided	Yes	No
1. Financial	1	2
2. Washing the PLWHA	1	2
3. Feeding	1	2
3. Administering Medication	1	2
4. Transporting PLWHA to health facility	1	2
5. Emotional/spiritual	1	2
5. Other (Specify……..		3

1.35. Are there things you would like to learn to improve your caregiving activities?

Yes	No

1	2

(If No, go to 1.37; if yes go to1.36)

1.36. If Yes, which of the following will be of help to you? **(more than one answer possible)**

	Yes	No
1. Learn more about HIV/AIDS	1	2
2. Learn how to better care for a PLWHA	1	2
3. Guided on how to access government assistance to care for the PLWHA	1	2
4. Other (Specify……..		3

1.37. On average how often in the past year have you sought medical treatment for the PWHA in your household ? **(read options to respondent)**

a. 2-3 times a month	1
b. Once a month	2
c. Less often than once a month	3
d. Other (specify……	4

1.38. How helpful overall do you find the health providers at the clinic/hospital when you visit with the PLWHA? (If never visited clinic/hospital with PLWHA, go to 1.39)

a. Very helpful	1
b. Helpful	2
c. Unhelpful	3
d. Very unhelpful	4

1.39. Is there somebody else in your family who knows about the PWHA's condition?

Yes	No
1	2

(If No, go to 1.41; If yes go to 1.40)

1.40. If Yes, who is this?
Person(s) who knows

	Yes	No	Don't know
1. My partner/husband	1	2	3
2. My other child(ren)	1	2	3
3. My grandchild(ren)	1	2	3
4. My sister/brother	1	2	3
5. My mother/father	1	3	3
6. Other (Specify…			

1.41. How do other members of your household behave towards the PLWHA? **(answer each) ?**

	Yes willingly	Yes reluctantly	No
1.They share meals with him/her	1	2	3
2.They share the same room with him/her	1	2	3
3.If no, why? (explain….			

1.42. Do people in the neighborhood know about the PLWHA condition? **(answer each)**

	Yes	No
1. Only one person knows	1	2
2. Some people know	1	2
3. It is common knowledge	1	2
4. Nobody knows	1	2
5. Don't know		3

1.43. During your caregiving of the PLWHA, does s/he ever? **(answer each)**

	Yes everytime	Yes sometimes	No/ Never
1. Shout or get angry with you	1	2	3
2. Hit or throw things at you	1	2	3
3. Accuse you of being responsible for his/her illness	1	2	3
4. Refuse to talk to you	1	2	3
5. Refuse to take food from you	1	2	3

1.44. Which other person(s) in this household who are sick (but not with AIDS) do you care for ? **(interviewer refer to the household grid for person code P3)**

Person	Code
1.	
2.	
3.	
4.	
5.	

I am now going to talk to you about person(s) in this household who have died in the last two years.

1.45. To your knowledge, is there someone in your household who died from AIDS in the past two years?

Yes	No	Not Sure
1	2	3

(**If No, go to 1.48 ; If Not sure, go to 1.48 ; If Yes, go to 1.46)**

1.46. What relationship was this (these) person(s) to you? **(multiple answers possible)**

	Yes	No
1. Child(ren)	1	2
2. Husband	1	2
3. Grandchild	1	2
4.Other (……		

1.47. On average how many months did you care for this/these person(s) before she died (PLWHA) from the time s/he/ they started to be sick with AIDS?

a. Less than one month	1
b. 1= < 4 months	2
c. 4 =< 7 months	3
d. 7 = < 10 months	4
e. > =10 months	5
f. Don't know	6

1.48. Did the person(s) who died live in this house all his/her life?

Yes	No
1	2

(If No, go to 1.49; if yes, go to 1.50)

1.49. If No, where did s/he/they live when s/he/they started to be sick with AIDS?

a. In another country	1
b. In the city/an urban area	2
c. In a rural area	3
d. Don't know	99

1.50. From whom did you first learn or hear about his/her/their illness?

a. From him/her/them	1
b. From a nurse/doctor at clinic/hospital	2
c. From a CHW (Community Health Worker)	3
d. From his/her partner	4
E. Other (specify….	5

1.51. Did this/these person(s) previously contribute to the household financially?

Yes	No
1	2

(If No go to 1.53; If yes, go to 1. 52)

1.52. Do you agree or disagree with the following:

	Agree	Disagree	Not sure
1. His/her death affected the household's finance severely	1	2	3
2. His/her death affected the household's finance moderately	1	2	3
3. His/her death did not affect the household's finance at all	1	2	3

SECTION 5

CARING FOR THE ORPHANS/GRANDCHILDREN

I am now going to ask you about the grandchildren you are caring for in this household (By caring I mean:cooking, feeding, washing, emotional, minding, counselling, disciplining, helping with school work, playing etc).

1.53. Are all your grandchildren at school?

Yes	No
1	2

(If No, go to 1.54; If Yes, go to 1.55)

1.54. If some are not at school, why are they not at school?
(more than one answer possible)

	Yes	No
1. There is not enough money for school	1	2
2. They (s/he) refuse to go to school	1	2
3. They (s/he) are too young to go to school	1	2
4. They (s/he) have finished school	1	2
5. They (s/he) are sick/disabled	1	2
6. They (s/he) are HIV infected	1	2
7. Other (Specify……	1	2

1.55. Who pays for their school fees and uniforms? **(more than one answer possible)**

	Yes	No
1. I pay for them	1	2
2. Other members of the family	1	2
3. Child support grant	1	2
4. Nobody pays for them/have no uniforms	1	2
5. Other (Specify…….	1	2
6. Don't know		

1.56. Why are you caring for these child(ren) ?

	Yes	No
1. I have no choice	1	2
2. Nobody else will/to care for them	1	2
3. They are part of my family	1	2
4. Other (specify…….		3

1.57. In which area(s) of caring for these children do you need support or help, and how much? **(read each option loud)**

Caring activity	**A lot of support/help**	**Some support/help**	**Don't need support/help**
1.Financial	1	2	3
2.Physical	1	2	3
3.Emotional	1	2	3
4.Social (e.g. discipline)	1	2	3
5.Other (specify…….	1	2	3

1.58. Which area(s) in which you spend money caring for the children are most costly; costly and least costly? **(interviewer must read options)**

Caring activity	**Most costly**	**Costly**	**Least costly**
1.School fees and uniforms	1	2	3
2. Health care	1	2	3
3. Food	1	2	3
4. Clothes	1	2	3
5. Transport	1	2	3
5. Other (Specify…….	1	2	3

1.59. Is there a grandchild(ren) who has been diagnosed with HIV in this household?

Yes	**No**	**Don't know**
1	2	3

(If No, go to 1. 61; If Don't know, go to 1.61; If Yes, go to 1.60)

1.60. If Yes, what are the major care needs of this (these) child(ren)? **(do not read the options to respondent)**

	Yes	No
1. Access to treatment (medication) for their condition	1	2
2. Counselling/emotional support	1	2
3. Nutrition support	1	2
4. Education (inform and encourage them about importance of taking treatment everyday)	1	2
5. Other(Specify……	1	2

SECTION 6
LOCAL/DISTRICT GOVERNMENT AND GENERALSUPPORT

Now I will ask you about the type of support you receive from government which helps you with your caregiving (by support I mean: government grants; free medicine; transport to clinic/hospital; food parcels)

1.61. Do you receive any support from government places (eg. Clinic; municipal offices)?

Yes	No
1	2

(If No, go to 1.63; if yes go to 1.62)

1.62. If Yes, indicate how much you agree or disagree with the following statement **(read each statement and circle the appropriate code)**

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1.The support I received from government is sufficient	1	2	3	4	5
2.The support I received from government is not sufficient	1	2	3	4	5
3.The support from government meet the basic needs of my caregiving	1	2	3	4	5
4.Government need to put more support for people who care for the PLWHA	1	2	3	4	5

1.63. If No, Which of the following support will help you meet your caregiving needs? **(read each option and circle the appropriate answer)**

Type of support

	Yes	No	Not Applicable
1. Nutrition (e.g.Food parcels)	1	2	3
2. Financial or money vouchers	1	2	3
3.Provide more room/space for people who care for PLWHA	1	2	3

1.64. To what extent do you agree with the following statements? **(read each statement)**

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
1.Government is committed to support PLWHA and those affected by HIV/AIDS	1	2	3	4	5	6
2.Government provide sufficient money to fight HIV/AIDS	1	2	3	4	5	6
3.Government provide enough support to households affected by HIV/AIDS	1	2	3	4	5	6
4.Government provides enough support to children affected by HIV/AIDS	1	2	3	4	5	6

Now I want to know about other forms of support other than from government that you receive

1.65. Do you belong to a faith/religious body?

Yes	No
1	2

(If No go to 1.68; if yes go to 1.66)

1.66. If Yes, to which faith/religious body do you belong?

a. Zion Christian Church (ZCC)	1
b.Catholic Church	2
c. Anglican Church	3
d. Methodist Church	4
e. Black Independent Church	5
f. Old Apostolic Church	6
g. Other religions:(specify……..	7

1.67. How often do you visit your place of worship?

a. Every Sunday	1
b. Twice a month	2
c. Once a month	3
d. Twice a week	4
e. Stop attending because of my caregiving responsibilities	5
f. Other (Specify…..	6

1.68. Do you belong to any of the following groups? **(read options to respondent)**

	Yes	**No**	**Not applicable**
1. Volunteer/Community support group (e.g. sewing group)	*1*	*2*	3
2. Women's support group	*1*	*2*	3
3.Men's support group	*1*	*2*	*3*
4. Burial society	*1*	*2*	*3*
5. Stokvels (money investment club)	*1*	*2*	*3*
4. Other (specify……..	*1*	*2*	*3*

THANK YOU VERY MUCH FOR YOUR COOPERATION

ANNEXURE 3

THE RESPONDENTS' RESOURCE PAMPHLET*

To be used to access support needed

NAME OF PROVINCE: Western Cape **Location type : Urban**

Organisation name	Address	Phone No.	Contact person	Resource offered
Philani Nutrition Center	Khayelitsha Site C Phaphani St 7784	(021)387 5124	Dr I. Le Roux	**Child Nutrition Advice and Support and health provision**
J.J Zwane Centre	NY7 Gugulethu Nyanga	021- 633 5033	Rev. Xhapile	**Referrals/food parcels/training**
Ilitha Labantu	22 Gugulethu Nyanga	021-633 2383	Ms M. Monakali	**HIV/AIDS Counselling and advice**
Beautiful Gate	Nyanga/Crossroads Nyanga	(021) 371 7107	Sr Frances	**HIV/AIDS advice, social work/counseling and support/ accommodation**
Missionaries of Charity (Mother Theresa's Nuns)	Khayelitsha Section E 7784	(021)361 3365	Sister Lwanga	**Food Distribution, HIV/AIDS education and accommodation**
MSF: Medicne Sans Frontieres	Khayelitsha Site B Sulani Drive 7784	(021)364 5490	Mr E. Goemaere	**Antiretroviral drug treatment, counseling and information**
GAPA Grandmothers Against Poverty and AIDS	Khayelitsha Section E Griffiths Mxenge 7784	(021)686 6369	Ms K. Brodrick	**General Support to Grandmothers PLWHAs**
NOAH Neighborhood Old Age Homes	Khayelitsha	(021)	Ms N. Mangcu	**HIV/AIDS Training and counseling to PLWHA and OVC caregivers**
Community Health Center Khayelitsha	Khayelitsha 7784	(021)360 3480	Sr L. Matinise	**Medical consultation, counseling, information and support**
SHAWCO	Nyanga Sithandathu Ave 7750	(021) 386 1603	Ms K. Ngozo	**Training, Food distribution, and counseling**
Treatment Action Campaign (TAC)	Khayelitsha Site B 7784	(021)364 5489	Ms T. Thembeka	**HIV/AIDS advocacy, legal advice and counseling**
Red Cross Society	Khayelitsha Site C 7784	(021)363 0016	Sr C. Nomala	**Training, food distribution, home based care, non statutory social work, advocacy and counseling**
Provincial Administration of the Western Cape (PAWC)	Khayelitsha Lingelethu Bld Bhonga Drive 7788	(021)361 4970	Ms P. Bhaca	**Social Work\Welfare services, referrals and counseling**

*Pamphlet for the Western Cape sub-sample. Similar pamphlets with information relevant to that setting were handed to respondents in the other two provinces, specific to the urban or non-urban setting.

ANNEXURE 4

INTERVIEW SCHEDULE FOR THE CASE STUDIES

I am going to ask you some questions about your household. By that I mean you must tell me about yourself, people who live in this house, those who are sick, children you care for, and also the support you need. I would like you to answer the questions frankly.

It is said that older persons who care for their ill children and sometimes their young grandchildren experience a lot of difficulties with caregiving.

1) Please tell me where you learnt about HIV and AIDS and what you know about the disease?

2) During caregiving to your sick child with HIV and AIDS, what specific things did or do you have to do to meet his/her needs?

3) With difficulties that you encounter during caregiving, do you ever ask for assistance or help from people in your neighbourhood?

4) If you do not ask for any help from neighbours, please explain why not?

5) In your opinion, how can the government assist older persons who care for PLWHA and their young grandchildren?

ANNEXURE 5

INTERVIEW SCHEDULE FOR GOVERNMENT KEY INFORMANTS

A. The government's response to the HIV/AIDS problem in the country was the initiation of the HIV/AIDS/STDs Strategic Plan (2000-2005) through the National Department of Health. This was a broad strategic plan intended to guide the country's response to this public health problem.

1. To your knowledge, what policies and programmes are available that conceivably provide support to older persons who care for PLWHA?

2. As you know, HIV/AIDS is a problem with Public Health and development implications. Do you see a role for the Health Department/Social Welfare and Development Department in providing support to older persons who care for PLWHA?

B. The plan recognises the need for collaboration between many actors, NGOs, and ministries and calls for all roleplayers to use the plan to guide their own interventions. Older persons are playing an unprecedented role as unskilled and older caregivers in the management of HIV/AIDS.

3. How may the needs of older persons and their organisations who care for PLWHA be put on the HIV/AIDS policy agenda?

4. How can older persons who care for PLWHA be involved in the process of HIV/AIDS policy development?

5. What barriers or reasons are there for the non participation of older persons or their organisations in HIV/AIDS policy development?

6. What can be done to overcome the barriers you mentioned above?

C. **Monitoring and evaluation are policy relevant activities, designed to assist policy makers and managers with direct feedback on a continuous basis to see whether implementation of the policy and other relevant activities are going according to plan.**

7. Please tell me, what mechanisms are there to monitor and evaluate the national HIV/AIDS policy/strategic plan in general?

8. If mechanisms are in place, are they evaluating the role played by older persons in managing this epidemic ?

9. If no mechanisms are in place, can you explain what reasons there could be for this?

D. **Policy change and implementation call for political, financial and managerial resources. Although not all policies will call for all these, a task is for policy makers and managers is to assess the availability of resources, and then to consider how they can be mobilized.**

10. To your knowledge, are there resources currently available to facilitate the involvement of older persons in the development and implementation of HIV/AIDS policy/strategic plan?

11. If No, could they be made available and how?

12. If Yes, who could make the resources available?

E. **Normally, most governments transfer authority or disperse some power in public planning, management and decision making from national to lower levels of government (e.g. province and local/district)**.

13. In your opinion, how can national policy makers enable local or district managers to co-ordinate the activities of the different roleplayers at local level, and work together to assist older person's household affected by HIV/AIDS?

14. As far as you know, does existing policy raise any research questions in relation to the impact of HIV/AIDS on older persons?

15. If yes, what are these research questions?

THANK YOU FOR YOUR CO-OPERATION

ANNEXURE 6

INTERVIEW SCHEDULE FOR NON PROFIT ORGANISATION

MANAGERS KEY INFORMANT INTERVIEWS

A. You have been identified as a representative of key NGO providing a crucial service to households caring for PLHWA. Government has developed a document (strategic plan/policy) for all role players working in this area to use when doing their work.

1. Are you aware of this national HIV/AIDS policy/strategic plan?

2. Does your organisation have the HIV/AIDS policy/strategic plan document in its possession?

B. Different organisations obtain such documents in different ways, for example, some through working with government officials. If your organisation has this document in its possession,

3. Where and how did your organisation obtain this document?

4. Was your organisation involved in the development of this policy/strategic plan? If yes, how was your organisation involved?

C. Monitoring and evaluation are policy relevant activities designed to assist policy makers and managers with direct feedback on a continuous basis, to assess whether implementation of the policy and other relevant activities are going according to plan. NGOs like yours might bring new ideas for policy change informed by your experience on the ground.

5. In your opinion, are there adequate mechanisms in place to involve NGOs like yours in monitoring and evaluation of the national HIV/AIDS Policy/Strategic Plan?

6. Does this address the role played by older persons in the management of this epidemic?

7. From your knowledge of the policy/strategic plan, are there barriers or reasons for the non participation of older persons in the development and implementation of the HIV/AIDS Policy/Strategic Plan?

8. If older persons and their support needs are overlooked in policies and programmes, how may this oversight be remedied?

D. We value the opinion of NGOs such as yours, because of your small size compared to government, your proximity to the community you serve, and your experience of local/district authorities (municipality).

9. Please tell me how the district, or local government could facilitate the involvement of older persons or their organisations in the process of future HIV/AIDS policy development to benefit older caregivers and thus the households in which they reside?

10. In your opinion, what are main HIV/AIDS issues that need to be addressed in relation to recognition and support of the role and contribution of older persons as caregivers?

THANK YOU FOR YOUR CO-OPERATION.

ANNEXURE 7

LETTER OF APPROVAL FROM THE UNIVERSITY OF CAPE TOWN FACULTY OF HEALTH SCIENCES' RESEARCH ETHICS COMMITTEE TO CONDUCT THE STUDY

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E53-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: [illegible]

31 October 2005

REC REF: 335/2005

Mr SG Petros
8 Spress Mews
Sipress Ave
Thornton
7460

Dear Mr Petros

PROJECT TITLE: THE ROLE OF OLDER PERSONS IN THE MANAGEMENT OF HIV/AIDS: AN ASSESSMENT OF THEIR CONTRIBUTION AND SUPPORT NEEDS IN THREE SOUTH AFRICAN PROVINCES

Thank you for your letter to the Research Ethics Committee, dated 20 October 2005.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study on the 26 October 2005.

Your comments to the queries raised are noted with thanks.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROF T. ZABOW
CHAIRPERSON

lenjedi

ANNEXURE 8

THE TEN CASE STUDIES

In-depth interviews were conducted with ten older carers whose households that formed part of the survey sample. The interviews constituted a part of the qualitative study component of the research design. The data gathered during the interviews were written up as case studies and are shown below. The case studies which are numbered from 1 to 10. Pseudonyms are used for the older carers who were interviewed.

Case study # 1

Mrs Nino, a 72 year old widow, had been living in Khayelitsha in a small three roomed house for more than ten years. In the house she lives with her daughter, and son and five of her grandchildren, a total of eight people live in the house. Mrs Nino has never attended school, received a government old age pension of R870 a month at the time and a child support grant for one of her grandchildren. The household had had no other source of income since her son took ill with AIDS two years ago and had lost his job owing to failing health. Mrs Nino's son had been sick for the past eight months with a persistent cough. Although he had been visiting different doctors for the cough, he never told Mrs Nino what the doctors' diagnosis was. He took cough mixture all the time. When he started to sweat at night and lost a lot of weight, she took him to the local health clinic where they diagnosed him as having tuberculosis (TB). When the doctor performed more tests on him it was found that his TB was a result of an underlying HIV infection. When Mrs Nino's son came out of the doctor's consulting room, he told her of the diagnosis.

Mrs Nino worried that one of her grandchildren was infected with the HI virus, as he had been coughing a lot and losing weight like his father. She planned to take him to a doctor as soon as she received her old age pension next time she had money. Mrs Nino explained that she had no knowledge about HIV and AIDS before she joined a local anti-AIDS and poverty organization. Before that, she had only heard about HIVand AIDS on the radio and sometimes on television. She claimed that the radio and television never explained properly what HIV and AIDS are. For example, she did not know what the difference between HIV

and AIDS is, who is at risk of contracting HIV and whether older persons can be infected with the virus. It never occurred to her that when she washed her son's bedding she should use protective hand gloves or plastic to protect herself from infection. This type of information is never shared over the radio or the television, she said.

Before her son became bedridden, Mrs Nino had had to use her pension money to hire a taxi to take him to the clinic and sometimes to a private doctor. She used to pray a lot for her son, and hoped that he would get better and go back to work, so that their lives could be normal again. However, things became worse and Mrs Nino had to spend more money on her son's health, and less money on food and other household essentials. A large portion of the pension income was spent on her son's needs, she explained. She said she was willing to accept help from anyone who could help her as the burden of caregiving had become too heavy for her to carry alone. However, although she was willing to accept help from anyone, she had not told people in her neighbourhood about the illness in her house. She believed that people might start to gossip about her family because of "this thing" (HIV and AIDS).

Lately she had been receiving assistance from an older persons' organisation in Khayelitsha. The organization has taught her a lot about HIV and AIDS, she said, more than what she had heard on the radio and television. The organisation had also equipped her with skills to generate income and she no longer depended only on her pension and the child support grant. Her son's illness had given her a lot of worries, she said, on top of which she was suffering from "high-high" (high blood pressure). She sometimes forgot to take her diabetes medication. She worried that with her own illnesses and old age, she might die first and did not know what would become of her son and grandchildren if she were no longer around. She believed it was her duty to look after her grandchildren as a grandmother, and besides, they are her own blood.

When asked how the government could best support her as a caregiver, she said that the government was already supporting her but the support was not sufficient. She explained that while she receives an old age pension and a child support grant, there is no specific support for caring for a PLWHA. She would accept any assistance the government could give her to address her sick son's health needs. She emphasised that what she and her household needed most was money. She wanted to be helped with money so that she could provide for the expensive nutritional needs of her sick son and send her grandchildren to school. One thing

she was grateful for was that her grandchildren were still listening to her when she spoke to them, and as such she had no discipline problems with them.

Case study # 2

Mrs Tiki-Tiki, 73 years old lives in a three-roomed shack in Khayelitsha with her sick husband, a daughter - their only child, and three school-going grandchildren. Her daughter used to live Johannesburg for a number of years where she went to look for work. Mrs Tiki-Tiki receives *inkam-nkam* (a government old age pension) as her main source of income. She said that often she could not wait for the end of the month so that she could receive *inkam-inkam* and cope with her household problems. She only attended sub-A and never completed primary school.

The daughter and her children used to come to visit Mrs Tiki-Tiki sometimes, especially over the Christmas holidays. Each time she visited, Mrs Tiki-Tiki would notice that the daughter appeared thinner than on previous visits. Whenever she commented to her daughter about her weight, she would say that her work in Johannesburg was hard and that she neglected herself sometimes and did not eat properly. The daughter never talked much about the children's father(s). The last time she came back from Johannesburg with her children she was very ill. She had said that the doctors in Johannesburg had told her she had contracted TB, but that if she took her TB treatment properly, she would get better.

Mrs Tiki-Tiki said her daughter's condition deteriorated fast and she was vomiting everything that she ate. She became weak and slept all the time. Sometimes she became confused and said things that no one could understand. She took her daughter to the clinic and a nurse told her that the doctor had said her daughter was very ill and that he was going to give her tablets called ARVs, which she must take every day. A social worker had then been invited into the doctor's room and had told Mrs Tiki-Tiki nicely that the doctor has found her daughter has AIDS. The daughter and mother must go home and the daughter must take the treatment the doctor prescribed for her.

Mrs Tiki-Tiki then took her daughter to a local traditional healer who claimed to be able to cure AIDS. The traditional healer gave her three bottles of herbs, and the mother was to give her two cupfuls of each bottle everyday in the morning and in the evening. The healer had

told the mother to keep bringing the daughter until she got better. Every time she visited she paid R100 for the consultation and treatment. She has lost count of how many times she had visited the healer, and the daughter's condition had never improved; she died in June 2007.

Mrs Tiki-Tiki had never told anyone in her community what her daughter's real illness was, as she was afraid people would gossip, and that might put her grandchildren's lives at risk and other children might not play with them. She had told her husband, and it was only she and him in the family who knew what had caused their daughter's death. The grandchildren knew only that their mother had died of TB. She was planning to tell them about the real cause of their mother's death when they are old enough to understand. Another thing that had made her reluctant to disclose her daughter's status was that people in her township who had HIV and AIDS are treated very badly; women, especially,are discriminated against and are sometimes killed violently by some community members. Some people, she explained, believe that women spread HIV.

Mrs Tiki-Tiki confided that her troubles were not over, as she now had to care for the three grandchildren left behind and her old and sickly husband. She did not receive a support grant for the children, as she still needed to obtain their papers (birth certificates). She felt that her and her husband's old age pensions were not enough to support three school-going children, two adults and a sick person who needs special treatment.

When she was asked how the government could best support her as a caregiver, she pointed out that she could no longer cope with her situation without support. She felt that the government should come to the rescue of older caregivers who have no training and sometimes no knowledge about HIV and AIDS. In her opinion, very few older persons know how to deal with HIV and AIDS in their family. Only carers who belong to organisations that address the disease in the community know how to deal with the challenges of HIV and AIDS. She emphasised that she lacked sufficient money and that the disease was impoverishing her and her household.

Case study # 3

Mrs Zozo, 64 years old never married. She was living in Khayelitsha in a two roomed shack with her daughter and five grandchildren when interviewed. Three of her grandchildren live temporarily with her other relatives in a neighbouring township because Mrs Zozo's house is

overcrowded. A total of seven people were thus living in the house. She was receiving no financial support from the government nor her extended family. Mrs Zozo has never been to school. She had previously held a job as a domestic worker, but had stopped working to take care of her daughter when she became seriously ill with double pneumonia. When she had taken the daughter to GF Jooste Hospital that time, the doctor had told her that AIDS had led to the pneumonia.

Mrs Zozo's daughter had brought all five of her children to her before she died. The father of the children had died earlier, from tuberculosis, according to the daughter. Mrs Zozo suspected that two of her grandchildren might be ill with the disease, as they were not eating and were losing weight rapidly. However, she had not taken them to the clinic or a hospital to be checked for TB or HIV, as she had not had a chance to and it was very expensive to take them in a taxi. What also discouraged her from doing so was a fear that the nurses would scream at her if she simply brought the children without knowing what was wrong with them. Some of the nurses at the clinic can be very harsh, she told.

Mrs Zozo said a shortage of money was a big problem in her household and she was the only breadwinner. She has been earning some income since she lost her job as a domestic worker by selling fruit and vegetables to people in the community. Sometimes when she had made a good profit, she would buy sheep heads and feet, which she would clean, cook and sell. She also made and sold handicrafts to earn income. She told that she acquired these skill from an older persons' organisation. "I believe that organisations such as these are good in bringing affected people together, to share their experiences and support one another," she explained. The NPO had also taught her a lot about the HIV and AIDS problem which her household and the community faced. Prior to joining the NPO she had only known about the disease from what she had heard on the radio. She had not told anyone in her community about the HIV and AIDS problem in her household. She simply told people who asked about her daughter's death that she had died from double pneumonia.

The eldest grandchild, who was 12 years, was about to start grade 11. It was due to the little things that Mrs Zozo sold to make ends meet that helped her to put the child through school. She is concerned though that the child might not finish school, owing to a lack of money in the house. Moreover, she feared that the child might come under bad influence, as most girls of that age in Mrs Zozo's community fall pregnant and leave school. Some of these girls

indeed leave school to associate with older men, who buy them nice clothes and cell phones, and impregnate them pregnant or give them sexually transmitted infections (STIs).

When asked how the government could best support her as a caregiver, Mrs Zozo said that it could help a great deal if it assisted persons like her with money for food, books, school uniforms, school fees and other expenses, which would help to keep grandchildren for whom they cared in school and prevent them from falling victim to HIV and AIDS. Moreover, the government should consider supporting single older caregivers who face "this problem" in their household directly. Older people like her, who are challenged by "this thing" in their home, are typically out of work their health is faltering and they live in poverty. They suffer a great deal under the burden of HIV and AIDS.

Case study # 4

Mrs Kamanga, 69 years old and widowed, had lived in various townships around Cape Town, but has resided in Khayelitsha the longest. She was living in a small four roomed shack house with four other people: a son (age 45), a daughter (age 28), and two grandchildren. An older son had built a shack at the back of the house and lived there with his wife and child, but all ate from the same pot. The household's only steady income was Mrs Kamanga's *indodla* (monthly old age pension) from the government. Mrs Kamanga stopped attending school in sub-B. Two of her younger sons had never worked since they left school about six years ago, and have been in and out of prison. One of these sons was diagnosed with HIV in 2001, and for the past two years he had been hospitalized intermittently for an uncurable skin condition. The doctors had told Mrs Kamanga that her son's skin condition was a form of cancer common in people infected with HIV. The last time she had visited the hospital was to take her son home. She was given tablets to give him every day, which he would have to take them for the rest of his life.

At first she had been convinced that AIDS can be cured like any other sexually transmitted disease. She had known of traditional healers who could cure sexually transmitted infections such as *gcusula* (gonorrheoa) and she believed that AIDS is a form of the *gcusula* condition. However, home based care volunteers at a local health clinic had convinced her that AIDS cannot be cured. She had also learned about AIDS from volunteers at a local older persons' organisation to which she belonged. She knew that everyone, including older persons, was at

risk of infection with the virus. She was aware moreover that she must wear protective equipment, such as hand-gloves, when she touches bodily fluids or washes her son's body.

One of her biggest worries was that her son sometimes refused to eat and became angry with her for no apparent reason and would blame her for all sorts of things, including his illness. Her other sons, when not in prison, were not helpful at all; they were always on the road, and would come home late in the evening and demand food which was not always available. Neither did her daughter in-law hold a steady job; whenever she had a part-time job, she preferred to buy alcohol with the money she earned. Mrs Kamanga's grandchildren both attended school. She did not know who would pay for their schooling if she suddenly died. Nonetheless, she believed that keeping her grandchildren in school was the only way they would have a better future.

She did not think that people in her neighbourhood knew about the true nature of her son's illness, as she has never told anyone about it. She felt that she was not ready to talk to outsiders about sensitive family matters such as "this illness": (AIDS). Moreover, she believed that people would gossip about her son and judge her as a mother who has failed to bring up her children in a moral way. Another thing was that people in her neighbourhood still have old-fashioned ideas about illness: when an ill person does not get cured, for example, people say the person has been bewitched, and then fingers might point at her.

When asked how the government could best support her as a caregiver, she said by providing her with a better house (i.e. bigger house with more rooms and an inside tap). She explained that to provide care properly for a PLWHA, easy access is needed to enough clean water for cooking and cleaning. Fetching water from a communal tap can be dangerous at night in an area like hers (Khayelitsha). She was thinking about obtaining a birth certificate for one of her grandchildren, so that she could apply for a child support grant for her the child's mother, Mrs Kamanga's daughter in-law is too busy drinking and has no time for her child. The grant will help to reduce the financial burden on Mrs Kamanga. However, the process of applying for a government grants takes a long time and the governments wants numerous documents before it will provide a grant.

Mrs Kamanga sometimes had to borrow money from money lenders, but her experiences with micro-lenders has not been good at all. They had charged her very high interest rates and

had sometimes confiscated and kept her identity document, until she repaid them in full. She knew that what the money lenders were doing was illegal, but said there was nothing she could do, as they were the only people who had money available when she needed it. Besides, they assisted a lot of older persons in her area who are in financial difficulty.

Mrs Kamanga explained that her household problems were "too much" for an older person like her and affected her health badly. She thought she might be suffering from stress, although she was not taking treatment for it. She was though being treated for hypertension, arthritis and diabetes. Hence, the government should support persons like her by increasing the amount of the old age pension, as she had to stretch her pension money "too much" in order to meet her own needs and those of other household members. The government should also involve older persons in HIV and AIDS related matters, and provide them with enough materials such as gloves to protect themselves from becoming infected.

Case study # 5

Mrs Zizo, 65 years old and widowed, had left school in Standard 6. She had been living in Nyanga in the same shack for the past five years. The house had four rooms, but no bathroom, electricity nor inside toilet. Seven people live in the house: a daughter (35 years), a son (23 years) and four school going grandchildren. The household's only steady source of income was Mrs Zizo's monthly *nkam-nkam* (social old age pension). Neither of her children were working, her daughter owing to ill-health and the son because he is wheelchair bound. To supplement her income, Mrs Zizo sold African beer and cooked sheeps' heads.

Mrs Zizo's daughter was diagnosed with HIV in 2004. The daughter did not disclose her condition to her when first diagnosed, and the mother only became aware of the daughter's HIV status after she took her to the clinic in 2006 because she had become seriously ill with diarrhoea and night sweats. The doctor who attended the daughter had invited her into the consulting room and told her the daughter was HIV positive and that he was going to put her on ARV treatment**.** He had explained what the tablets were for, Mrs Zizo had not fully understood how ARVs work in the body. The only thing she remembered was that she should give her daughter the treatment at specific times of the day everyday. Only when she had joined a community based organization that fights against AIDS and stigma in her community had Mrs Zizo learned about ARVs. It is from the home based care volunteers at

the organization that she learned ARVs are given when the body's soldiers are no longer able to defend itself from germs because of the HI virus (germ), and the body's defence is weakened. The ARVs help the body fight the invading HIV germ in the body, but do not cure an infected person and that is why her daughter had to take them everyday for the rest of her life. Prior to joining the organization, Mrs Zizo had heard about the disease from the television and radio, but she did not recall that these sources had ever spoken of ARVs.

Mrs Zizo had not yet spoken to her relatives about her daughter's condition, nor people in the neighbourhood. She was afraid that people would start to gossip about her child and about her for failing to be a good parent. She thought that people still viewed the disease as infecting other people and not as a community problem that put everyone at risk. She said she spent sleepless nights thinking about the bad thing (HIV and AIDS) that has happened in her house. She had borrowed money from friends to pay for transport to take her daughter to traditional healers, preachers and clinics to get help for her in the past few months, but the daughter's condition was "on and off" and was getting worse by the day.

Mrs Zizo complained of having a constant headache ever since she was told that her daughter had HIV. Her diabetes had become worse, even though she was being treated for the condition. She believed that her health was deteriorating because of the situation (HIV and AIDS) in her house. When asked how the government could best support her as a caregiver, Mrs Zizo said that although the government was doing something by giving free tablets (ARVs) to the PLWHA, she needed support with money and food to take care of the ill person. She said she was advised by the home based care volunteers to buy and prepare nutritious food for the PLWHA, but the food they recommended was expensive and is not the food she usually prepares for everyone in her house. The PLWHA needed special food that goes to the blood (nutritious food), not just any food such as samp or mealie meal and potatoes. She also felt the government should help people affected by HIV and AIDS by giving them proper houses with piped water inside and electricity. She felt that her grandchildren have developed chest problems because of the paraffin fumes, and she lives under constant worry of her shack catching fire. Proper houses would provide a better environment in which to care for ill persons, as she would then not have to go outside to fetch water for cooking and washing.

She felt she was not coping at all with her caregiving responsibilities, as she has to divide her attention between the PLWHA and her school going grandchildren. The government should involve older persons in the fight against the epidemic. The government should send representatives to churches, old age pension paypoints and other places to teach older persons about the disease and how to protect themselves against infection.

Case study # 6

Mrs Zoe, 77 years old had lived in Zolani in Ashton for the past 20 years. Five people lived in her house: two adults who were her unemployed sons, two orphaned grandchildren and she. Mrs Zoe was receiving a social old age pension and a child support grant for each of the grandchildren. The household had no other income, since the death of her daughter. Her daughter had died three years earlier due to an AIDS related condition (tuberculosis). Mrs Zoe, said she has never attended school because her parents were poor and could not send her to school.

Mrs Zoe knew that AIDS is caused by a germ (virus) called HIV, which weakens the body's soldiers (immune system), making it vulnerable to infection by germs. She did not think her two sons and the grandchildren were HIV positive since none had shown any signs that they were infected. She had not taken her grandchildren for testing, even though their mother had died of an AIDS related condition. She had found it difficult to care for her daughter when she was alive, and clean the house and look after her young grandchildren at the same time. When her daughter was sick there had been no money or transport to take her to the day hospital (Community Health Centre). On rare occasions, some members of her extended family would give her money when things were very difficult in the house. She had never told anyone in her family nor anybody in her neighbourhood about her daughter's status because she knew people would start saying painful things about it, and even start isolating her grandchildren. Mrs Zoe was supplementing the government grants by selling fruit, vegetables and sweets in her community.

Mrs Zoe was very worried about her grandchildren's future, as she felt she was very old and her health was bad, and she might die at anytime and there would be no-one to care for her young grandchildren. She wanted her grandchildren to remain at school until they finished, so they could live a better life than she had, which has been full of difficulties, and

characterised by ill health and worries. Her daughter's death had affected the household badly. First, it was the sadness of the loss of a loved one, and then the loss of a source of income, as her daughter had been the only person in the household to hold a steady job.

When asked how the government could best support her as a caregiver, she said through help with money to enable her to buy food, clothes and take her grandchildren to a doctor in time when they fell ill. The child support grant was not enough to meet all a child's needs, including school expenses. The government needed to consider exempting older persons who provide care for PHWA and orphaned children from paying school fees, and other things such as electricity and medicine. In addition, the government should develop programmes on HIV and AIDS that address older persons' needs and not only focus on the younger generation. The day hospital, she felt, should supply people affected by the disease with enough material such as gloves, plastic aprons, as she used to struggle a great deal trying to get gloves when her daughter was alive.

Case study #7

Mrs Tibo, 59 years old had been living in Macassar, outside Cape Town for the past 15 years. Nine people lived in her four roomed house: she, her husband, a son and two daughters, and four grandchildren. Mrs Tibo was receiving a child support grant and was employed part-time, but no-one else in the household worked. She reported that she could not do any other job because she has only standard two.

Mrs Tibo's daughter was diagnosed HIV positive in 2003. At first she had not believed the diagnosis, but a doctor confirmed it for her. Mrs Tibo thought that HIV was contracted by persons who sell their bodies (commercial sex workers) for money, and by those who "shoot" (intravenous drug users), but not by people in steady relationships like her daughter. This information, she pointed out, she had heard from the radio and people in the community, but which was obviously not the full story. Besides believing that people in steady relationships and married people were safe from the disease, she also believed that older persons were not at risk of contracting HIV as the virus only infects young people who are sexually active.

A major difficulty for Mrs Tibo was buying and preparing nutritious food for her sick daughter. The food was expensive, and she also needed money to transport the daughter and sometimes her grandchildren, when they were not well, to the day hospital. She was not coping at all, she said, with the caregiving demands on her and her grandchildren's needs such as food, schooling expenses such as clothes and transport, and providing a home for them. Although her daughter received free counselling and treatment at the day hospital, there was no privacy for PLWHA as all those who came for ARVs treatment had to sit on one side of the waiting room. However, she believed that no one else in her neighbourhood know about her daughter's health condition, as she had not felt confident enough to talk openly about her daughter's status, even though an increasing number of young people were dying in her neighbourhood and it was rumoured that it is because of the disease. She did not talk about her daughter's condition to people in the neighbourhood, as she knew they would say bad things about her and her daughter behind their backs.

Mrs Tibo spent sleepless nights thinking and worrying about her sick daughter. She had been visiting the doctor a lot recently, since she started having difficulty in falling asleep. The doctor had told her that she was suffering from depression and had to put her on treatment. She also thought that she suffered from stress, for which she was not receiving treatment.

When asked how the government could best support and help her as a caregiver, she said by fast-tracking her application for a social pension, so that she would be able to care for her sick daughter properly. She felt that the government should consider exempting older persons in situations like her's from paying for electricity, school fees and public transport. Her house was too small for five adults and four fast growing young children, who need their privacy and space to do school work, and she needed a bigger house with a shower and flush toilet inside so that she does not have to go outside to collect water in the evening and when it is cold and raining. She complained that her small house makes nursing difficult for her.

Case study # 8

Mrs Bidi, 66 years old and widowed, was living in a two roomed house in Nyanga. She lives in the house with her daughter and son, and five grandchildren. Two other grandchildren lived with relatives elsewhere. The ages of the grandchildren in Mrs Bidi's house ranged from 3 to 17 years. Mrs Bidi's daughter was HIV positive. She had been told of her status at

the clinic at the time of her last delivery. Mrs Bidi had learned about the infection from a doctor who was treating lesions on her body. Before the daughter died, Mrs Bidi's did not know what was wrong with her. Mrs Bidi also did not know what is AIDS, who may contract the disease and whether older persons are at risk. She did not know that one should wear gloves or protective equipment when attending a PLWHA's sores and washing his or her clothes. She believed anyway that it is inappropriate to put on protective equipment to wash a child as it would indicate rejection of her own flesh and blood, which would be culturally frowned upon. She only started using gloves and sometimes plastic bags after she had been advised to do so by home based care volunteers, who visit once a week to help and advise her on caring for the PLWHA. She had never told anyone in her family or neighbourhood about her daughter's status for fear of rejection and to protect her grandchildren from being harassed by other children.

Mrs Bidi used her social old age pension income to meet the financial demands of her household. Everyone in the house, including her grandchildren who lived elsewhere, benefitted from the grant. She sometimes approached money lenders to borrow money which she normally paid back at the end of the month, when she received her pension. She did not think she would survive if she did not receive the grant. To supplement the income, she engaged in income generation activities such as baking and selling fat cakes, as well as cooked sheep heads and intestines. Her greatest difficulty was a lack of money for day to day expenses to sustain her family. She complained that it had become difficult to pay for electricity, food for eight people and other necessities. Sometimes she had to stop buying electricity and use paraffin lamps, candle sticks and paraffin stoves for heating, lighting and cooking family meals.

She also complained about her advanced age which limited her in what she could do and she worried about losing her independence. She no longer had strength and her health was deteriorating. She believed that all the difficulties she was experiencing in her house were affecting her health negatively. She had been to a doctor a lot in the past eight months, and he had diagnosed her to have stress, depression and diabetes. She suspects she has "high-high" (high blood pressure) as well, because of never ending headaches she suffers. The doctor has put her on treatment and a strict diet, which she says she cannot afford owing to her poor financial status.

When asked how the government could support her as a caregiver, she said by providing her 18 year old grandchild with a child support grant. The grandchild does not qualify for the grant, owing to age, but has financial needs such as school expenses. The government could also support her by providing food for the family, since her grandchildren do not have enough to eat. Although she is experiencing difficulties with the grandchildren, she believes it was her duty as a grandparent to support them and they were her own blood anyway. Mrs Bidi, said she would also like to be educated on HIV and AIDS and on how to care properly for someone who is sick from AIDS. She said she would like to keep her grandchild at school so that she does not become uneducated like her.

Case study # 9

Mrs Rory, 73 years old and widowed, was living in a three roomed house in Macassar with her sister, a son and five grandchildren. She was receiving a social old age pension, but no child support grant for any of her age eligible grandchildren. The only other source of income in her household was from odd jobs that one of her granddaughters did on occasions. The local hospice was helping Mrs Rory to apply for a foster care grant. Mrs Rory had passed standard ten but cannot remember what year was it when she got her certificate.

Mrs Rory's granddaughter had AIDS. Mrs Rory had not known anything about HIV and AIDS until she heard about it from volunteers at the Hospice and from reading the materials they gave her. She had only heard from neighbours' gossip that it was a disease of young people. She believed that the youth contracted the disease because they drink a lot of alcohol and did not eat properly. She thought that if young people ate properly and stopped consuming too much alcohol, the body could be strong and able to resist the disease. Once one has AIDS, like with TB, one must eat properly and take tablets everyday if one wants to survive it (AIDS). Since being told by the volunteers about AIDS, and from what she had read, she now knew that older people can contract the disease if they are sexually active and do not protect themselves by wearing condoms.

Mrs Rory had experienced financial difficulty in getting her granddaughter to the community health centre and buying her the special food that she was supposed to eat. Sometimes the hospice provided her with small food parcels, but which lasted for less than a week. Her granddaughter has been ill for more than three years, and in all of that time she had been

receiving free treatment and counselling at the community health centre. One had to wake up early in the morning though to avoid the long queues and waiting at the health centre. As far as she knew, she did not think there were people in her family and in the community who know about her granddaughter's real illness. Everyone thought it was tuberculosis. Mrs Rory felt that she wanted to keep her granddaughter's illness secret, and she and the granddaughter had agreed to do so. However, her granddaughter's health situation was putting a great deal of stress on Mrs Rory, and she had been taking sleeping tablets at night. She prayed a lot about her granddaughter's condition and hoped it would be healed one day. She said she believes in miracles.

Mrs Rory had recently been diagnosed with depression and hypertension, on top of a heart condition she had been battling with for over eight years. She was worried that if all the diseases killed her, there will be no one to look after her grandchildren. When asked how the government could support her, she said by increasing the amount of her old age pension, so that she could meet her household needs. The government could also help her with food, as the food parcels she receives from the hospice are not even enough for the nutrition needs of the sick person. Lastly, she said the government could provide her with a bigger house, or add more rooms to the over-crowded three roomed house she presently occupies. Overcrowding in her house, she pointed out, was not conducive for caregiving.

Case study # 10

Mrs Noor, 64 years old and widowed, was living in a three roomed house in Ashton with six of her grandchildren. Another three grandchildren lived with her sister in De Doorens. Mrs Noor received a child support grant for only one of her grandchildren . The household had no other source of income. Mrs Noor had recently lost her part time job. She has passed standard eight. Mrs Noor has applied for a grant for the other grandchildren and a social pension for herself but things were taking a long time at the government office. Mrs Noor earned income from buying reject children's clothes from local wholesalers and selling them in the community for a small profit.

Mrs Noor knows that AIDS is caused by a germ (virus) called HIV. She believes strongly though that AIDS is punishment from God of wrongdoers and there is nothing that one can do about it. Her orthodox knowledge about HIV and AIDS comes from different sources: the

television, radio, pamphlets and health professionals. She knows that anybody can contract the disease, and that older persons are at equal risk if they are sexually active and do not use preventive measures such as condoms. Older persons who care for PLWHA and use bare hands to clean sores and bedding of the sick person are also at risk. When asked why she believed the disease is a punishment from God, she said the bible says there will come a time were there will be incurable diseases because people have sinned in the eyes of God. AIDS is such a disease, she reasoned. When asked, what about babies who are infected, could they have sinned, she said God does things in mysterious ways.

Mrs Noor told she could not cope with looking after her sick child and the rest of her family because there was not enough money to buy groceries, pay for electricity, and transport her sick child to the clinic. There was neither anyone to help her with the caregiving. However, she did not have to pay for her child's treatment. She felt bad that her grandchildren could not have the same things as other children of their age. She was trying her best to generate extra money to cover their basic needs such as food and paying for their school expenses. Her main concern was what would happen to them, especially the very young ones, if she suddenly died, as she was weak and sickly herself.

As far as she knew, it was common knowledge in the immediate neighbourhood, she said, that her child had AIDS. The home based care volunteers visit her house every Wednesday and people in the community know their vehicle carries materials for people sick with AIDS. Besides, she tells those who want to know about her child's illness; disclosing the illness has helped her overcome fear for AIDS. She hoped and prayed that medical people would find a cure for the disease soon, as it caused a lot of difficulties and suffering for people like her who have to provide care day in and day out. On the other hand she felt relieved that she did not have to constantly hide the sickness in her house and give herself more stress.

Mrs Noor said the difficulties in her house were killing her slowly. She had visited a doctor in 2005 and was diagnosed with high blood pressure and diabetes. She believed her high blood pressure was a result of her many worries. Her legs and hands joints were also very painful especially when it was cold, which was not being treated. She was afraid she might die before her child, and that there would be no one who will care for him and her young grandchildren.

When asked how the government could support her with her problems, she said through financial support so that she could buy enough food for her family. Her grandchildren sometimes went to school without having enough food to eat, and they could not learn on an empty stomach. She was trying her best though to put food on the table. She would also like to be more informed about HIV and AIDS. She would be very happy, Mrs Noor said, if the government could extend her house, so that she could have enough room to provide care optimally and to have her own privacy and space to relax. The government should also include older people in programmes and not only talk only to young people. “We as old people are facing this problem in our homes and communities.”

ANNEXURE 5

INTERVIEW SCHEDULE FOR GOVERNMENT KEY INFORMANTS

A. The government's response to the HIV/AIDS problem in the country was the initiation of the HIV/AIDS/STDs Strategic Plan (2000-2005) through the National Department of Health. This was a broad strategic plan intended to guide the country's response to this public health problem.

1. To your knowledge, what policies and programmes are available that conceivably provide support to older persons who care for PLWHA?

2. As you know, HIV/AIDS is a problem with Public Health and development implications. Do you see a role for the Health Department/Social Welfare and Development Department in providing support to older persons who care for PLWHA?

B. The plan recognises the need for collaboration between many actors, NGOs, and ministries and calls for all roleplayers to use the plan to guide their own interventions. Older persons are playing an unprecedented role as unskilled and older caregivers in the management of HIV/AIDS.

3. How may the needs of older persons and their organisations who care for PLWHA be put on the HIV/AIDS policy agenda?

4. How can older persons who care for PLWHA be involved in the process of HIV/AIDS policy development?

5. What barriers or reasons are there for the non participation of older persons or their organisations in HIV/AIDS policy development?

6. What can be done to overcome the barriers you mentioned above?

C. Monitoring and evaluation are policy relevant activities, designed to assist policy makers and managers with direct feedback on a continuous basis to see whether implementation of the policy and other relevant activities are going according to plan.

7. Please tell me, what mechanisms are there to monitor and evaluate the national HIV/AIDS policy/strategic plan in general?

8. If mechanisms are in place, are they evaluating the role played by older persons in managing this epidemic ?
9. If no mechanisms are in place, can you explain what reasons there could be for this?

D. Policy change and implementation call for political, financial and managerial resources. Although not all policies will call for all these, a task is for policy makers and managers is to assess the availability of resources, and then to consider how they can be mobilized.

10. To your knowledge, are there resources currently available to facilitate the involvement of older persons in the development and implementation of HIV/AIDS policy/strategic plan?

11. If No, could they be made available and how?

12. If Yes, who could make the resources available?

E. Normally, most governments transfer authority or disperse some power in public planning, management and decision making from national to lower levels of government (e.g. province and local/district).

13. In your opinion, how can national policy makers enable local or district managers to co-ordinate the activities of the different roleplayers at local level, and work together to assist older person's household affected by HIV/AIDS?

14. As far as you know, does existing policy raise any research questions in relation to the impact of HIV/AIDS on older persons?

15. If yes, what are these research questions?

THANK YOU FOR YOUR CO-OPERATION

ANNEXURE 6

INTERVIEW SCHEDULE FOR NON PROFIT ORGANISATION MANAGERS KEY INFORMANT INTERVIEWS

A. You have been identified as a representative of key NGO providing a crucial service to households caring for PLHWA. Government has developed a document (strategic plan/policy) for all role players working in this area to use when doing their work.

1. Are you aware of this national HIV/AIDS policy/strategic plan?

2. Does your organisation have the HIV/AIDS policy/strategic plan document in its possession?

B. Different organisations obtain such documents in different ways, for example, some through working with government officials. If your organisation has this document in its possession,

3. Where and how did your organisation obtain this document?

4. Was your organisation involved in the development of this policy/strategic plan? If yes, how was your organisation involved?

C. Monitoring and evaluation are policy relevant activities designed to assist policy makers and managers with direct feedback on a continuous basis, to assess whether implementation of the policy and other relevant activities are going according to plan. NGOs like yours might bring new ideas for policy change informed by your experience on the ground.

5. In your opinion, are there adequate mechanisms in place to involve NGOs like yours in monitoring and evaluation of the national HIV/AIDS Policy/Strategic Plan?

6. Does this address the role played by older persons in the management of this epidemic?

7. From your knowledge of the policy/strategic plan, are there barriers or reasons for the non participation of older persons in the development and implementation of the HIV/AIDS Policy/Strategic Plan?

8. If older persons and their support needs are overlooked in policies and programmes, how may this oversight be remedied?

D. We value the opinion of NGOs such as yours, because of your small size compared to government, your proximity to the community you serve, and your experience of local/district authorities (municipality).

9. Please tell me how the district, or local government could facilitate the involvement of older persons or their organisations in the process of future HIV/AIDS policy development to benefit older caregivers and thus the households in which they reside?

10. In your opinion, what are main HIV/AIDS issues that need to be addressed in relation to recognition and support of the role and contribution of older persons as caregivers?

THANK YOU FOR YOUR CO-OPERATION.

ANNEXURE 7

LETTER OF APPROVAL FROM THE UNIVERSITY OF CAPE TOWN FACULTY OF HEALTH SCIENCES' RESEARCH ETHICS COMMITTEE TO CONDUCT THE STUDY

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E53-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: [illegible]

31 October 2005

REC REF: 335/2005

Mr SG Petros
8 Spress Mews
Sipress Ave
Thornton
7460

Dear Mr Petros

PROJECT TITLE: THE ROLE OF OLDER PERSONS IN THE MANAGEMENT OF HIV/AIDS: AN ASSESSMENT OF THEIR CONTRIBUTION AND SUPPORT NEEDS IN THREE SOUTH AFRICAN PROVINCES

Thank you for your letter to the Research Ethics Committee, dated 20 October 2005.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study on the 26 October 2005.

Your comments to the queries raised are noted with thanks.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROF T. ZABOW
CHAIRPERSON

lenjedi

ANNEXURE 4

INTERVIEW SCHEDULE FOR THE CASE STUDIES

I am going to ask you some questions about your household. By that I mean you must tell me about yourself, people who live in this house, those who are sick, children you care for, and also the support you need. I would like you to answer the questions frankly.

It is said that older persons who care for their ill children and sometimes their young grandchildren experience a lot of difficulties with caregiving.

1) Please tell me where you learnt about HIV and AIDS and what you know about the disease?

2) During caregiving to your sick child with HIV and AIDS, what specific things did or do you have to do to meet his/her needs?

3) With difficulties that you encounter during caregiving, do you ever ask for assistance or help from people in your neighbourhood?

4) If you do not ask for any help from neighbours, please explain why not?

5) In your opinion, how can the government assist older persons who care for PLWHA and their young grandchildren?

REFERENCES

Abdool-Karim, Q. 1995. The HIV/AIDS epidemic. *South African Health Review*. Durban: Health Systems Trust.

Aber, L., & Richter, L. 2005. *Family and school-based interventions to improve psychosocial outcomes of children affected by HIV/AIDS*. Unpublished paper. Durban: Child, Youth and Family Development, Human Sciences Research Council.

Abel, T., & Werner, M. 2003. HIV risk behaviour of older persons. *European Journal of Public Health*. 13: 350.

Aboderin, I. 2007. Development and ageing policy in sub-Saharan Africa: Approaches for research and advocacy. *Global Ageing*. 4(3): 7–22.

Aboderin, I., & Ferreira, M. 2008. *Linking ageing to development agendas in sub-Saharan Africa*: *Challenges and approaches*. World Demographic Association Discussion Paper Series. Available: www.wdassociation.org [2008, March 26].

Abt Associates, and Health Economics and HIVAIDS Research Division (HEARD). 1999. HIV/AIDS and health. *AIDS Toolkits*. Durban: Abt Associates, University of Natal.

Abuja Declaration. 2001. The declaration on HIV/AIDS, tuberculosis and other related infectious diseases. Special Summit devoted specifically to address The Challenges of HIV/AIDS, Tuberculosis and Other Related Infectious Diseases. Abuja.

Actuarial Society of South Africa (ASSA). 2004. ASSA AIDS and demographic models: ASSA2002. Available: www.assa.org.za [2006, June 17].

Adamchak, D.J., Wilson, O.A., Nyanguru, A., & Hampson, J. 1991. Elderly support and Intergenerational Transfer in Zimbabwe: An analysis of Gender, Marital status, and Place of residence. *The Gerontologist*, 41(4): 505-513.

Adler, W.H., Bender, B.S., & Nagel, J.E. 1998. Immune function and AIDS in the older patient. *Infection Medicine*. 15(12): 842–846.

Adler, W.H., & Nagel, J.E. 1994. Acquired immunodeficiency syndrome in the elderly. *Drugs Aging*. 4(5): 410–416.

Adult Abuse Review. 2002. World Health Organization release report on adult abuse. Available: http://www.wordbridges.net/elderabuse/AAR/Vol1Issue2/WHOreport.html. [2008, March 29].

AED-USAID. 2003. *Multisectoral response to HIV/AIDS: a compendium of promising practices in Africa*. USAID-PVO Steering Committee on Multisectoral Approaches to HIV/AIDS. New York: USAID Bureau for Africa, Office of Sustainable Development.

Africa Strategic Research Corporation. 1999. *Abuse of the elderly in South Africa*. Pretoria: Human Sciences Research Council.

African (Banjul) Charter on Human and Peoples' Rights. 1986. (OAU Doc. CAB/LEG/67/3) Available: www1.umn.edu/humanrts/instree/z1afchar.htm
[2007, June 27].

African Development Bank. 2005-2009. *Country strategy paper*. Manzini, Swaziland: ADB.

African Development Forum (AFD). 2000. *The African consensus and plan of action: Leadership to overcome HIV/AIDS*. Addis Ababa, Ethiopia, December 3–7.

African Union (AU)/ HelpAge International (HAI). 2003. *AU Policy Framework and Plan of Action on Ageing*. Nairobi: HAI Africa Regional Development Centre.

Aged Support Society of Malawi (ASSOM). 2005. *Report on the research study on the aged persons in Malawi: Towards understanding their situation and challenges.* Manzini: Department of Population Studies, University of Swaziland.

Aggleton, P. 2000. *Comparative analysis: Research studies from India and Uganda. HIV and AIDS related stigma, discrimination and denial.* Geneva: UNAIDS.

AIDS Law Project n.d. *Women, HIV and AIDS: HIV/AIDS current law and policy*. Johannesburg: Centre for Applied Legal Studies, Johannesburg: University of the Witwatersrand.

AIDS Policy Law. 1997. Biting was a homicide. 12(9): 12. Available: www.medsite.com. [2006, September 13].

Akinsola, H. A. 2001. Fostering hope in people living with AIDS in Africa: The role of the Primary Health Care worker**.** *Australian Journal of Rural Health*. 9: 158–165.

Akintola, O. 2004. *A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal.

Akukwe, F.N. 1992. *Senior citizens: A policy dilemma.* Onitsha, Nigeria: Veritas.

Albert, S.M., & Cattell, M.G. 1994. *Old age in global perspective*. New York: G.K. Hall.

Allander, J.A., & Spradley, B.W. 2005. *Community Health Nursing: Promoting and protecting the public's health.* 6th ed. London: Lippincott Williams & Wilkins.

Alonzo, A.A., & Reynolds, N.R. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3): 303–315.

Anderson, S., & Kaleeba, N. 1994. AIDS care in the family. *World AIDS Day News*, 3:1. Available: www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=A…
[2006, November 8].

Ankrah, M.E. 1991. AIDS and the social side of health. *Social Science & Medicine.* 32(9): 967–980.

Ankrah, M. E. 1993. The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care*. 5(1).

Anyango, O.M., Momanyi, K.J., & Muriuki, J. 1995. *Feelings and experiences of single HIV-positive women about their children*. Paper presented in the IXth International Conference on AIDS and STDs in Africa, Kampala, Uganda.

Appay, V., & Rowland-Jones, S.L. 2002. Premature ageing of the immune system: the cause of AIDS? *Trends in Immunology*. 23(12): 580-585.

Appleton, J. 2000. "At my age I should be sitting under that tree": The impact of AIDS on Tanzanian lakeshore communities. *Gender and Development.* 8(2): 1927.

Arhihenbuwa, C. 2003. *Health and culture: Beyond the Western paradigm*. London: Sage.

Arndt, C., & Lewis, J.D. 2000. The macro implications of HIV/AIDS in South Africa: a preliminary assessment. (Special submission.) *South African Journal of Economics*.

Aubel, J. 2001. Strengthening grandmother networks to improve community nutrition. *Gender and Development.* 9(2): 30–35.

Aubel, J. 2005. *Grandmothers: A learning institution*. Washington, D.C.: Creative Associates and USAID.

Aubel, J., Sihalathavon, D., & Kopke, D. 1997. *Participatory health education project with grandmothers in Laos, Vietnam.* (unpublished).

Aubel, J., Toure'; I., & Diagne, M. 2004. Senegalese grandmothers promote improved maternal and child nutrition practices: The guardians of tradition are not averse to change. *Social Science & Medicine*, 59: 945–959.

Auvert, B., Taljaard, D., & Sobngwi-Tambekou, J. et al. 2005. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: The ANRS 1265 Trial. *Public Library of Science Medicine*. 2(11): 1-11.

AVERT. n.d. *Sexually transmitted diseases. Symptoms, treatment and facts*. West Sussex: AVERT. Available: www.avert.org/disclaimer.htm. [2005, November 10].

Awusabo-Asare, K., & Anarfi, J.K. 1992. Health seeking behaviour of persons with HIV/AIDS in Ghana. *Health Transit Review*, 7: 243-259.

Ayiga, N., Ntozi, J. P.M., & Ahimbisibwe, F. E. et al. 1999. Causes, patterns differentials and consequences of AIDS mortality in Northern Uganda. *The Continuing African HIV/AIDS Epidemic*. 139–154.

Babbie, E. 1983. *The practice of social research*. Belmont, CA: Wadsworth.

Babbie, E. 1990. *Survey research methods*. 2nd ed. Belmont, CA: Wordsworth.

Babbie, E. 2001. *The practice of social research*. 9th ed. Wadsworth/Thomson Learning.

Bachmann, M.O., & Booysen, F.L. 2002. Health and economic impact of HIV/AIDS on South African households: A cohort study. *Journal of British Medicine and Public Health*. 3(14): 1–8.

Baggaley, R., Sixaxe, T., & Gaillard, P.2000. Involving men in MTCT intervention, October, submitted to *AIDS Care*.

Barrientos, A., & Lloyd-Sherlock, P. 2003. Non-contributory pensions and poverty prevention. A comparative study of Brazil and South Africa. Report. Manchester: IDPM and HelpAge International.

Barnett, T., & Blaikie, P. 1992. *AIDS in Africa*. London: McMillan.

Barnett, T., & Whiteside, A. 2002. *AIDS in the 21st Century: Disease and globalization: Critical perspectives on Southern Africa* 54. Ann Arbor, MI: State University Press.

Bartlett, G. 1997. Management of healthcare workers infected with HIV: The SHEA position paper. *The Hopkins HIV Report.* New York: John Hopkins University.

Bateman, C. 2001. Can KwaZulu-Natal hospitals cope with the HIV/AIDS human tide? *South African Medical Journal.* 91(5): 364–368.

Baum, A., & Nesselhof, S. 1998. Psychological research and the prevention, etiology, and the treatment of AIDS. *American Psychologist.* 43(11): 900-903.

Baum, F., & Sanders, D. 1995. Can health promotion and primary health care achieve health for all without a return to their more radical agenda. *Health Promotion International.* 10: 149-160**.**

Baumgarten, M., Hanley, J.A., Infante-Rivard, C. et al. 1994. Health of family members caring for elderly persons with dementia. *Annual International Medicine.* 120: 126-132.

Baydar, N., & Brooks-Gunn, J. 1994. The dynamics of child support and its consequences for children. In *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS. Research Report on Recommendations.* Cape Town*:* Children's Institute, University of Cape Town.

Baylies, C. 2002. HIV/AIDS and older women in Zambia: Concern for self, worry over daughters, towers of strength. *Third World Quarterly.* 23: 351–375.

Benatar, S. 1991. Medicine and health care in South Africa – five years later. *The New England Journal of Medicine.* 325: 30–36.

Benatar, S. 2004. Health care reform and the crisis of HIV and AIDS in South Africa. *New England Journal of Medicine.* 351: 1.

Bennell, P., Hyde, K., & Swainson, N. 2002. *The impact of the HIV/AIDS epidemic on the education sector in sub-Saharan Africa: A synthesis of findings and recommendations of three country studies.* Sussex: Department of Health, University of Sussex.

Beresford, B. 2002. Failing to deliver. The government is battling to provide a welfare safety net for families affected by HIV/AIDS. *Weekend Mail and Guardian*, October 11 p.8.

Bergin C., O'Reilly, M., Goha, J. et al. 2000. Incidence of sexually transmitted diseases amongst an elderly cohort attending a Genito-urinary medicine clinic. *Journal of the European Academy of Dermatology and Venereology*. 5(3): 218-221.

Berg, B.L. 2001. *Qualitative research methods for the social sciences* 4th ed. Boston: Allyn & Bacon.

Berman, H. J. 1987. Adult children and their parents: Irredeemable obligation and irreplaceable loss. *Gerontological Social Work with Families,* 10:21–34.

Besley, M.A. 2005. *AIDS and the family: Policy options for a crisis in family capital*. New York: Sage.

Birdsall, K., & Kelly, K. 2005. *Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey*. Johannesburg: Centre for AIDS Development, Research and Evaluation (CADRE),

Bittles, A.H. 1991. Biological aspects of human ageing. In *Psychiatry in the elderly*. Jacob, R., & C. Oppenheimer, Eds. Oxford: Oxford Medical Publications.

Blaikie, A. 1999. Ageing: old visions, new times? *Lancet*, 354: 4.

Blau, P.M. 1964. *Exchange and power in social life*. New York: Wiley.

Blenkner, M. 1965. Social work and family relationships in later life with some thoughts on filial maturity. In *Social structure and the family: Generational Relations.* Shanas, E., & G. F. Streib, Eds. Englewood Cliffs, NJ: Prentice Hall.

Blieszner, R., & Hamon, R. R. 1992. Filial responsibility: Attitudes, motivators, and behaviors. In *Gender, families and elder care*. Dwyer, J. W., & R. T. Coward, Eds. Newbury Park, CA: Sage.

Blinkhoff, P., Bukanga, E., & Syamalevwe, B. et al. 1999. Under the Mpundu tree: Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt, *Strategies for Hope Series,* 14 London: ActionAid.

BOLD. 2006. Grandmothers at the AIDS conference. The Toronto statement. *BOLD*. 17(1): 30–31.

Boneham, M.A., & Sixsmith, J.A. 2006. The voices of older women in a disadvantaged community: Issues of health and social capital. *Social Science & Medicine*. 62: 269–279.

Booysen, F. 2002. Financial responses of households in the Free State Province to HIV/AIDS-related morbidity and mortality. *South African Journal of Economics*. 70(7).

Booysen, F., & Van der Berg, S. 2005. The role of social grants in mitigating the socio-economic impact of HIV/AIDS in two Free State communities. *South African Journal of Economics*. 73: 546–563.

Bowling, A. 1997. *Research methods in health: Investigating health and health services*. Buckingham, PA: Open University Press.

Brabeck, M., Brown, L., & Espin, C. L. et al., 1997. Feminist theory and psychological practice. In *Shaping the future of feminist psychology: Education, research, and practice.* Worell, J., & N. Johnson, Eds. Washington, DC: American Psychological Association, pp.15-35.

Bradshaw, D., Nannan, N., & Laubscher, R. et al., 2000. *South African national burden of disease study: Estimates of provincial mortality. Eastern Cape Province*. Parow: South African Medical Research Council.

Bredenkamp, C. 1999. *Falling through the cracks? Income security and the South African social security system*. Unpublished Masters dissertation. Stellenbosch:
University of Stellenbosch.

Bromley, D.B. 1986. *The case-study method in Psychology and related disciplines.* Chichester: Wiley. 51, 56 & 372.

Browne, C. 1994. Feminist theory and social work: A vision for practice with older women. *Journal of Applied Social Sciences*, 18: 5–16.

Browne, C. 1995. A feminist lifespan perspective on aging. In *Feminist practice in the 21st Century*. N. Van Den Berg, Ed. Washington, D.C.: NASW Press.

Brown, J.R. 1996. *The I in science: Training to utilize subjectivity in research*. Oslo: Scandanavian University Press, Universiteitforget AS.

Browne, C. 1998. *Women, feminism, and aging*. New York, NY: Springer.

Bryman, A. 1989. *Research methods and organisation studies*. London: Unwin Hyman.

Bumagin, V.E., & Hirn, K.F. 2001. *Caregiving: A guide for those who give care and those who receive it*. New York: Springer.

Burns, N., & Grove, S.K. 2001. *The practice of nursing research – conduct critique and utilization*. 4th ed. Philadelphia: W.B. Saunders.

Buch, E., Mathambo, V., Ferrihno, P. et al. 2003. *Leakages in PMTCT care in a district hospital in KwaZulu-Natal, South Africa*. Durban: Health Systems Trust.

Burman, E. 1994. Interviewing. In *Qualitative methods in Psychology*. Banister, P.E., I. Burman, Parker, M. Taylor, & C. Tinal, Eds. Milton Keynes: Open University Press.

Burman, S. 1996. Intergenerational family care: legacy of the past, implications for the future. *Journal of Southern African Studies*. 22(4): 585–598.

Burton, L.M. 1992. Black grandparents rearing children of drug-addicted parents: Stressors, outcomes, and social service needs. *Gerontologist.* 12: 744–751.

Butt, A.A., Dascomb, K.K., De Salvo., K.B. et al. 2001. Human immunodeficiency virus infection in elderly patients. *South African Medical Journal.* 94(4): 397–400.

Calasanti, T. 1999. Feminism and gerontology: Not just for women. *Hallym International Journal of Aging* 1: 44–55.

Caldwell, M. 2001. *Prospects for the aged in the developing world*. Paper read in the UNPFA Symposium on the Aged, IUSSP conference, Salvador de Bahia.

Caliandro, G., & Hughes, C. 1998. The experience of being a grandmother who is the primary caregiver of her HIV positive child. *Nursing Research.* 47: 107–113.

Callaghy, T.M. 1993. The state as lame Leviathan: Patrimonial administrative state in Africa. In *The African state in transition.* Ergas, Z., Ed. New York: St.Martin's Press, 87-116.

Campbell, D.T. 1979. "Degrees of freedom" and the case study. In *Qualitative and quantitative methods in evaluation research*. Cook, T.D., & C.S. Reichardt, Eds. Beverly Hills, CA: Sage.

Cameron, E. 1993. Legal rights, human rights and AIDS: The first decade. Report from South Africa. *AIDS Analysis Africa*, 3: 3-4.

Canfield, J. 1997. *Philosophy of meaning, knowledge and value in the* 20th *century*. London: Routledge.

Carael, M., & Holmes, K. 2001. The multicentre study of factors determining the different prevalences of HIV in sub-Saharan Africa. *AIDS.* 15(4): 5-14.

Carballo, M., & Carael, M. 1988. Impact of AIDS on social organization. In *The global impact of AIDS.* Alan, R., & I. Fleming, Eds. New York: John Hopkins Bloomberg, 81-94.

Carroll, J.S., & Johnson, E.J. 1990. Decision research: A field guide. *Applied Social Research Methods Series*, 22. London: Sage.

Carvalho, S., & White, H. 1997. Combining the quantitative and qualitative approaches to poverty measurement and analysis: the practice and the potential. *World Bank Technical Paper* 366. Washington, D.C.: World Bank.

Case, A. 2001. *Does money protect health status? Evidence from South African pensions*. Princeton: Princeton University Press.

Case, A. 2004. Does money protect health status? Evidence from South African Pensions. In *Perspectives on the economics of Aging*. Wise, D., Ed. Chicago: University of Chicago Press.

Case, A., & Deaton, A. 1996. Large cash transfers to the elderly in South Africa. *The Economic Journal.* 108: 1330-1361.

Cassiem, S., & Streak, J. 2001. *Budgeting for child socio-economic rights: Government obligations and the child's rights to social security and education*. Cape Town: Idasa.

Centre for Development and Population Activities (CEDPA). 1975. *Faith community responses to HIV/AIDS. Integrated reproductive health and HIV/AIDS for NGOs, FBOs & CBOs. 2.* Washington, D.C.: USAID.

Center to Improve Care of the Dying (CEDA). n.d. *Faith community responses to HIV/AIDS. Integrating reproductive* h*ealth and HIV/AIDS for NGOs, FBOs & CBOs*. Training manual series. 1. Washington, D.C. Available: www.gwu.edu/u~cicd/tookit/caregive.htm. [2006, April, 04].

Centres for Disease Control (CDC). 2008. HIV/AIDS among persons aged 50 and older. *CDC HIV/AIDS fact*. Available: http://www.cdc.gov/hiv/topics/over50/resources/factsheets/pdf/over50.pdf. [2008, November 22].

Chaklader, H. 2004. *Baseline survey on older people*. Dhaka: Bangladesh Women's Health Coalition.

Challis, L., Fuller, S., Henwood, M. et al. 1994. Investigating policy co-ordination: issues and hypotheses. In *Public sector management: Theory, critique and practice*. McKevitt, D., & Lawton, Eds. London: Sage.

Charlton, K.E., Kawana, B., & Hendriks, M. 2009. An assessment of the effectiveness of growth monitoring and promotion practices in the Lusaka district of Zambia. *Nutrition*, 25(10): 1035–1049.

Chela, C.M. 1995. *Assessing the cost-effectiveness of home based care in Zambia*. Paper presented in the 2nd International Conference on Home and Community Care for Persons Living with HIV/AIDS, Montreal.

Child Health Policy Institute & The Children's Rights Project. 2000. *Policy and legislation framework. Children with disabilities and chronic illnesses: Their right to social security*. Paper presented in the National Workshop on Social Assistance for Children with Disabilities and Chronic Illnesses, Cape Town, May 15-16.

Children's Institute. 2002. *Social security benefits for children and families*: *Comment made to the Department of Social Development on the Report of the Committee of Inquiry into Comprehensive Social Security System.* Cape Town: Children's Institute, University of Cape Town.

Chima, R., Chima, I., & Azie, U. 2004. *Ageing and HIV/AIDS: Impact, responses and weak links*. Paper read in the African Conference on Ageing, Johannesburg, August 18-20**.**

Chimwaza, A., & Watkins, S. 2002. Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care*, 16(7): 795-807.

Chodorow, N.J. 1989, 1991. *Feminism and psychoanalytic theory*. New York: Yale University Pres.

Clair, J.M., Karp, D.A., & Yoels, W.C. 1993. *Experiencing the life cycle*. Springfield, IL: Thomas.

Clandinin, D.J., & Connelly, F.M. 2000. *Narrative inquiry; Experience and story in qualitative research.* San Francisco: Jossey-Bass.

Clapham, C. 1996. *Africa and the international system*: *The politics of survival*. Cambridge: Cambridge University Press.

Clark, R.E., & Drake, R.E. 1994. Expenditure of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal.* 30(2): 145-163.

Clark, S.J., Collison, M.A., & Kahn, K. 2005. Returning home to die circular labour migration and mortality in northeast South Africa. *Scandanavian Journal of Public Health* (under review).

Clausen, F., Sandberg, E., & Ingstad, B. et al. 2000. Morbidity and health care utilization among elderly people in Mmakgodi village, Botswana. *Journal of Epidemiology and Community Health*. 54(1): 58-63.

Cleveland, C.J. 2007. *The human development index: going beyond income.* New York: United Nations Development Programme. Available: www.eoearth.org/article/Botswana's_Human_Development_Index_for_2004>. [2008, January 29].

Cloud, G.C., Browne, R., Salooja, N. et al. 2003. Newly diagnosed HIV infection in an octogenarian: elderly are not "immune." *Age Ageing*. 32(3): 353-354.

Coll-Seck, A. 2001. *Access to treatment.* UNAIDS/UNDP Workshop, Harare, Zimbabwe, February 15.

Commission for Africa (CfA). 2005. *Our common interest*. Report of the Commission for Africa. London: Commission for Africa Secretariat.

Commission for Gender Equality (CGE). 2005. Submission to the South African Parliamentary National Assembly. Portfolio Committee on Social Development: Older Person's Bill. Cape Town.

Commission for Social Care Inspection (SCI). 2006. Institutional elder abuse. *Journal of Elder Abuse and Neglect*. 10: 43– 60.

Coopoo, S. 2000. *The women's budget series. Women and local government review,* 2000. Community Agency for Social Enquiry and Parliamentary Committee on the Quality of Life and Status of Women. Cape Town: IDASA.

Coovadia, H.M., & Coutsoudis, A. 2002. Problems and advances in reducing transmission of HIV-1 through breastfeeding in developing countries. *AIDScience*. 1(4): 1-13.

Cowgill, D.O. 1986. *Aging around the world*. Belmont, CA: Wadsworth.

Cowgill, D.O., & Holmes, L.D. 1972. *Aging and modernization*. New York: Appleton-Century-Crofts.

Creswell, J.W. 1994. *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Creswell, J.W. 1998. *Qualitative enquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Creswell, J.W. 2003. *Research design: Qualitative, quantitative and mixed methods approaches.* 2nd ed. London: Sage.

Critical Health Editorial Collective. 1988. AIDS in South Africa: progressive perspectives. *Critical Health*. 22.

Cumming, E., & Henry, W. 1961. *Growing old*. New York: Basic Books.

Curtis, M. 1996. *Marxism: The inner dialogue*. 2nd ed. London: Transaction.

Davids, A., Skinner, D., & Letlape, L. 2002. *Our children our future: From vision to innovative impact, community responses to orphans and vulnerable children*. Pretoria: Human Sciences Research Council.

Dorrington, R., Johnson, L., Bradshaw, D. et al. 2006. *The demographic impact of HIV/AIDS in South Africa: National and provincial indicators for* 2006. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

Dawson, D.A, Cynamon, M. & Fitti, J.E. 1987. AIDS knowledge and attitudes: Data from the national health interview survey. *Advance Data*. 146: 1-10.

Dayritt, M.M., Monzon O.T., & Bassaca-Sevilla, V. et al. 1987. Emerging patterns of HIV infection and control in the Phillipines. *Western Journal of Medicine*. 147(6): 723-725.

Dayton, J., & Ainsworth, M. 2002. *The elderly and AIDS: Coping strategies and health consequences in rural Tanzania*. Population Council Publication, No. 160. New York: Population Council.

Dean, K. 1986. Lay care illness. *Social Science & Medicine*. 22: 275-84.

De Gorgolas, M., Bello E., Garcia Vazquez, E. et al. 1999. In old age …AIDS. Is it worth to initiate antiretroviral treatment? Review of 37 patients more than 60 years of age. *Annals of Medicine International*. 16(6): 273-2766.

Deininger, K., Garcia, M., & Subbarao, K. 2001. *AIDS-induced shock as a systemic shock: Magnitude, impact and programmatic interventions in Africa*. Washington, D.C.: World Bank.

De Jong, J. 2003. *Making and impact in HIV/AIDS: NGO experiences of scaling up*. London: ITGD Publishing.

De Maeseneer, J., Willems, S., De Sutter, A. et al. n.d. Primary Health Care as a strategy for achieving equitable care: A literature review commissioned by the Health Systems Knowledge Network. Available: www.who.int/social_determinants/resources/csdh_media/primary_health_care_2007_en.pdf. [2008, November 29].

Denzin, N.K. 1989. *Interpretive biography*. Newbury Park, CA: Sage.

Denzin, N.K., & Lincoln, Y.S. 2003. Strategies of qualitative inquiry. 2nd ed. Thousand Oaks, CA: Sage.

Drew, R.S., Mgombane, G., & Nyaruwa, T. 1997. Estimating coverage of a community based home care programme. *Tropical Doctor*. 27: 210-214.

Department for International Development, UK. 2005. *Social transfers and chronic poverty: Emerging evidence and the challenge ahead*. London: DFID.

Devereux, S. 2002. Can social safety nets reduce chronic poverty. *Development Policy Review*. 20(5): 657-675.

Development Research and Training. n.d. Ugandan participatory poverty assessment process (UPPA). Kampala Ministry of Finance, Planning and Economic report. Uganda.

de Vos, A.S., & van Zyl, C.G. 1998. The grounded theory methodology. In *Research at grass roots. A primer for the caring professions*. A.S. de Vos, Ed. Pretoria: Van Schaik. 265-276.

Diof, W. 2000. Adult learning in a non-western context: The influence of culture in a Senegalese farming village. *Adult Education Quarterly*. 51(1): 32-44.

Disney, R. 2002. Africa in crisis. Hazards rise for prime-age adults. *Insights. Pension for life?* 42. Sussex: The University of Sussex.

Dlamini, N. 2005. *The main challenges in mainstreaming gender***.** Paper presented in the: 7th AIDS Impact Conference, Cape Town, October.

Doll-Yogerst, D. n.d. *The key informant approach*. Available: www. uwex.edu/ces/pdande/progdev/pdf/keyinform.pdf. [2005, December 18].

Dolbin-MacNab, M.L., & Targ, D.B. 2003. Grandparents raising their grandchildren: Guidelines for family life educators and other family professionals. In *Working with custodial grandparents*. B. Hayslip, & J.H. Patric, Eds. New York: Springer. 213-228.

Donabedian, A. 1980. *Explorations in quality assessment and monitoring*. Ann Arbor, MI: Information Management, Health Administration Press.

Drench, M.E., & Losee, R.H. 1996. Sexuality and sexual capacities of elderly people. *Rehabilitation Nursing*. 21(3): 18-23.

Drevenstedt, J. 1976. Perceptions of onsets of young adulthood, middle age, and old age. *Journal of Gerontology*. 31: 53-57.

Drinka, T.J., Smith, J.C., & Drinka, P.J. 1987. Correlates of depression and burden for informal caregivers of patients in a geriatrics referral clinic. *Journal of the American Geriatrics Society*. 35: 522-525.

Duflo, E. 2003. Grandmothers and granddaughters: Old age pensions and Intra-household Allocation in South Africa. *World Bank Economic Review*. 17: 1-25

Dugbatey, K. 1999. National health policies: sub-Saharan African case studies (1980-1990). *Social Science & Medicine*. 49(2): 223-240.

Du Guemy, J. 2001. *The elderly, HIV/AIDS and sustainable rural development*. Sustainable Development Department, Food and Agriculture Organization, United Nations (FAO). Available: www.fao.org/sd/2002/PE0101a_en.htm. [2005, March 22].

Dunkin, J.J., & Anderson-Hanley, C. 1998. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology*. 51(1): 53-60.

Ehrlich-Sachs, S., & Sachs, D. 2004. Africa's children orphaned by AIDS. *The Lancet*. 364: 1404.

Ekpeyong, S. 1995. The structural adjustment programme and the elderly in Nigeria. *International Journal of Ageing and Human Development*. 41(4): 267-279.

Eldemire-Shearer, D. 1999. Change, family life, coping strategies and seniors, *Aging and Development Report*, London: Help Age International. Available: www.helpage.org/Resources/Policyreports/main_content/1118337994-011/AgeingAfricaSummary.pdf [2007, December 12].

Emerson, R.M. 1972. Exchange theory, part II: In *Exchange relations and networks*. Berger, J., Zeldich, M., & Anderson, Eds. Boston: Houghton-Mifflin, pp. 58-87.

Emerson, R.M. 1976. Social exchange theory. *Annual Review of Sociology*, 2: 335-362.

Engelhardt, J., Brubaker, T., & Lutzer, V. 1998. Older caregivers of adults with mental retardation: Service utilization. *Mental Retardation*. 26: 191-195.

Esu-Williams, E. 2003. Involving youth in the care and support of people affected by HIV and AIDS. *Horizons Research Summary*. Washington, D.C.: Population Council.

Fatimi, Z., & Avan, I . 2002. Demographic, Socio-economic and Environmental determinants of utilization of antenatal care in rural setting of Sindh, Pakistan. *Journal of Pakistan Medical Association*. 52: 138-142.

Feldman, P. H., Nadash, P., & Gursen, M. 2001. Improving communication between researchers and policy makers in long-term care: Or, researchers are from Mars; policy makers from Venus**.** *The Gerontologist*. 41(3): 312.

Ferreira, M. 1997. South Africa's social pensions system: Who benefits and how? In *Ageing in changing societies: Africa preparing for the next millennium*: Ferreira, M., N. Apt, & A. Kirambi, Eds. London: Brook Green Print.

Ferreira; M. 1999. The generosity and universality of South Africa's social pension system, *the Courier*, 176: 55-56.

Ferreira, M. 2000. Growing old in the new South Africa. *Ageing International*. 25: 32-46.

Ferreira, M. 2004. Elder abuse in Africa: What policy and legal provisions are there to address the violence? *Journal of Elder Abuse & Neglect*, 16: 17-32.

Ferreira, M. 2006. HIV/AIDS and older people in sub-Saharan Africa: Towards a policy framework. In Age, ageism, and HIV and AIDS. J. Sykes & S.J. Aziz .Eds. Global Ageing. Canada: HelpAge International Press. 56-69).

Ferreira, M., & Charlton, K.E. 1996. Towards an integrated, community based social and health care programme for older residents of Mitchell's Plain: A study report. Cape Town: HSRC/UCT Centre for Gerontology.

Ferreira, M., Charlton, K.E., & Mosaval, Y. 1998. Retired farm workers, farm evictions and the "dop" system: An exploratory study in three towns in the Western Cape Province. Study report. Cape Town: HSRC/UCT Centre for Gerontology.

Ferreira, M., Gurland, B., Bloom, H. et al. 2007. Study to Understand and Foster the Functioning and Involvement of Contributive Elders (SUFFICE). Report on a pilot study towards a health intervention. Cape Town: University of Cape Town, Institute of Ageing in Africa.

Ferreira, M., Keikelame, J., & Mosaval, Y. 2001. Older women as carers to children and grandchildren affected by AIDS: a pilot intervention project. Cape Town: University of Cape Town, Institute of Ageing in Africa.

Ferreira, M., & Kowal, P. 2006. A minimum data set on ageing and older persons in sub-Saharan Africa. Process and outcome. *African Population Studies*, 21(1): 19-36.

Ferreira, M., & Kalula, S.Z. 2007. Ageing and human rights South Africa. In:. *Human rights in an ageing world: Perspectives from around the world*. Macleod, R., Ed. London: International Longevity Centre-United Kingdom. 7-10.

Ferreira, M., & Lindgren, P. 2008. Elder abuse and neglect in South Africa: a case of marginalization, disrespect, exploitation and violence. *Journal of Elder Abuse and Neglect*. 20(2): 91-107.

Ferreira, M. (monica.ferreira@uct.ac.za). 2008. [Personal communication, 15 November] to G. Petros (sabela.petros@uct.ac.za)

Ferreira, M., & Kalula, S. 2009. Ageing women and health: Emerging caregiving needs in sub-Saharan African countries. *BOLD*, 19(4): 2–12.

"Filthy" health clinic has become a gutter: Patients say they are treated with lack of respect. 2008. *Cape Argus,* November 19, 16.

Fink, A. 1995. *The survey handbook.* Thousand Oaks, CA: Sage.

Fisher, A.A., & Foreit, J.R. 2002. *Designing HIV/AIDS intervention studies: An operations research handbook.* New York: Population Council Inc.

Fitzpatrick, A., Power, N., & Cooper, L. et al., 2004. Barriers to health care access among the elderly and who perceives them. *American Journal of Public Health*, 94(10): 1788-1794.

Flick, U. 1998. *An introduction to qualitative research: Theory, method and applications.* London: Sage.

Forbes, A. 2000. Raising grass-roots demands for microbiocides in the USA. Global campaign for STI/HIV prevention alternatives for women. *Sexual Health Exchange*. 4: 12-13.

Ford, G.G. 1986. Illness behaviour in the elderly. In *Self care and health in old age*. Dean, K., T. Hickey, & B.E. Holstein, Eds. London: Croom Helm. 130-166.

Forrester-Kibunga, K. 1999. *The situation of older women in Tanzania*. Dar es Salaam, Tanzania. London: HelpAge International.

Forrester-Kibunga, K., & Dianga, A. 2000. Victimisation and killing of older women: Witchcraft in Mnagu District, Tanzania. *Southern African Journal of Gerontology*. 9: 29-32.

Foster, G. 2002. Understanding community responses to the situation of children affected by AIDS: Lessons for external agencies. Draft paper prepared for the UNRISD project on HIV/AIDS and development. March 2002.

Fouad, D. 2004. *Role of elderly people in the era of HIV/AIDS in Africa*. Paper read in the African Conference on Ageing, Johannesburg, August 18-20.

Fowler, F.J. 2002. *Survey research methods*. 3rd ed. Thousand Oaks, CA: Sage.

Friedman, I. 2002. Community based health workers. South African Health Review. Durban: Health Systems Trust Report.

Frohlich, J. 2005. The impact of AIDS on the community. In *HIV/AIDS in South Africa*. Abdool Karim, S., & Abdool Karim, Q., Eds. New York: Cambridge University Press,

Fuglesang, A. 1982. *About understanding: ideas and observations on cross-cultural understanding,* Uppsala: Dag Hammarskjold Foundation.

Fuller-Thomson, E., & Minkler, M. 2000. African-American grandparents raising grandchildren: A national profile of demographic and health characteristics. *Health and Social Work Journal.* 25: 109-118.

Gallagher, D., Rappaport, M., Benedict, A. et al. 1985. *Reliability of selected interview and self-report measures with family care givers*. Paper presented in the Gerontological Society of America annual meeting, New Orleans, November.

GAPA. n.d. Grandmothers against AIDS and poverty. Available: www.gapa.org.za. [22, October 2009].

Garbus, A. 2003. *HIV/AIDS in South Africa: Country AIDS analysis project*. San Francisco. University of California Press.

Garenne, M., Tollman, S.M., & Kahn, K. et al. 2006. Fertility trends and net reproduction in Agincourt, rural South Africa: 1992-2004. *Scandanavian Journal of Public Health,* 32(1).

Geffen, N. 2006. How the health minister hurts South Africa. *Business Day*. September 19, 9

Gelfand, D.E. 1994. *Aging and ethnicity: Knowledge and services*. New York: Springer.

George, L.K., & Gwyther, L.K. 1986. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist.* 26: 253-259.

Gerdes, L. 1988. *The developing adult*. 2nd ed. Durban: Butterworths.

Gergen, M.M. 1988. Narrative structures in social explanation. In *Analysing everyday explanation*: *A casebook of methods*. Antaki, C., Ed. Carlifonia: Sage. 94-112.

Giese, S., Meitjies, H., Croke, R., & Chamberlain, R. 2003. *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS. Research report on recommendations.* Cape Town*:* Children's Institute, University of Cape Town.

Gilborn, L.Z., Nyonyintono, R., Kabumbuli., A. et al. 2004. *Making a difference for children affected by AIDS: baseline findings from operations research in Uganda*. Available: www.pop-council.org/pdfs/horizons/orphansbsln-pdf [2006, March 25].

Gilks, W, Richardson, S., Spiegelhalter, D. et al. 1998. *Sexual health and health are: care and support for people with HIV/AIDS in resource poor settings*. Health and Population Occasional paper. London: Department for International Development, UK.

Gleneagles G8 Summit Communique. 2005. Available: http://www.g8.gov.uk/ [2005, November 10].

Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity*. New York: Simon & Shuster.

Goldin, C.S. 1994. Stigmatization and AIDS: Critical issues in public health. *Social Science & Medicine*. 39(9): 1359-1366.

Goodwin, J. 1999. Enhancing the care of people with HIV. *Harvard AIDS Review*. Spring, 16-17.

Gordon, S.M., & Thompson, S. 1995. The changing Epidemiology of human immunodeficiency virus infection in older persons. *American Geriatrics Society Journal*. 43: 7-9

Gould, B., & Huber, U. 2002. HIV/AIDS, poverty and schooling in Tanzania and Uganda. British Society for Population Studies meeting on Poverty and Well-being in HIV/AIDS affected African countries. London, January 8. Available: www.socstats.soton.ac.uk/choices/Gould%20Paper.doc [2005, September 14].

Green, J.C., Caracelli, V.J., & Graham, W.F. 1989. Towards a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*. 11(3): 255-274.

Griffin, C. 1986. Qualitative methods and female experiences: young women from school to the job market. In *Feminist social psychology: developing theory and practice*. Wilkinson, S., Ed. Milton Keynes: Open University Press. 173-191.

Grundy, E., & Bowling, A. 1991. The Sociology of aging. In: *Psychiatry in the elderly*. Jacob, R., & C. Oppenheimer, Eds. Oxford: Oxford Medical Publications.

Guba, E.G. 1978. *Towards a methodology of naturalistic inquiry in education evaluation*. CSE Monograph Series in Evaluation no. 8. Los Angeles: University of California, Center for the Study of Evaluation.

Gupta, G.R. 2003. Lessons from the past, challenge for the future: An overview of HIV/AID in Africa. Plenary presentation, HIV/AIDS in Africa: what works. Organised by Centre for Global Development and John Snow, Inc.

Gurmessa, M. 1999. *The social effects of AIDS on the elderly*. Addis Ababa: Addis Ababa University.

Guthrie, T. 2000. *Social security for children in South Africa: Options and improvements. Submission to the Committee of Inquiry into Comprehensive Social Security System.* Cape Town: Child Health Policy Institute.

Hansen, K. 1994. The costs of hospitaal care at *Government Health Facilities in Zimbabwe with Special emphasis on HIV/AIDS Patients*. Harare, Zimbabwe: Blair Research Institute, Ministry of Health and Family Welfare.

Hardon, A., Boonmongkon, P., & Streefland, P. et al. 1995. *Applied health research manual. Anthropology of health and health care*. Armsterdam: University of Armsterdam.

Hardy, C. 1999. A vicious cycle: AIDS and gender oppression. Complaints officer, commission on gender. *Women's Month.* August 9: 1.

Harris, D.K. 1990. *Sociology of aging*. 2nd ed. New York: Harper & Row.

Hasselkus, B. 1993. Aging and health. In *Willard and Spackman's Occupational_therapy*. Hopkins, H.L., & H.D. Smith, Eds. Philadelphia: J.B Lippincott.

Harvey, C., Siphambe, H., & Segosebe, E. 2000. *Globalisation and sustainable human development: Progress and challenges for Botswana*. Occasional paper. Geneva. United Nations Development Programme.

Havard, J., & Haslegrave, M. 2000. *Impact of HIV/AIDS on the health professions in developing countries*. Paper presented in the Commonwealth Medical association, Conference on "The HIV/AIDS Crisis: A Commonwealth Response," London, December 7.

Hayslip, B., & Kaminski, P.L. 2005. Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist*. 45(2): 262-270.

Head, J. 1992. *Transformation of the structure of poverty in the struggle for an effective HIV/AIDS policy*. Paper presented in the Ruth First Memorial Colloquium, University of the Western Cape, Cape Town.

Heller, T., & Factor, A. 1993. Aging family caregivers: Support resources and changes in burden and placement desire. *American Journal on Mental Retardation*, 98: 417-426.

HelpAge International. 1998. Ageing: the forgotten development issues. *Ageing and Development.* 1: 1-3.

HelpAge International. 1999a. Making ends meet in Tanzania. *Ageing and Development.* 4. London. HAI.

HelpAge International. 1999b. Summary report on ageing. *Ageing and Development*. London. HAI.

HelpAge International. 2000. A world without poverty: time to include older people? An analysis of current topics in ageing. *Ageing and Development.* 6: 6-7.

HelpAge International. 2001. HIV/AIDS: Why strategies must include older people. An analysis of current topics in ageing. *Ageing and Development*. 8: 6-7

HelpAge International. 2002a. News and analysis of issues affecting the lives of older people. Chronic poverty in South Africa. *Ageing and Development.* 12: 4.

HelpAge International. 2002b. Practical issues in ageing and development. The Second World Assembly on Ageing. *Ageways.* 60: 4-10.

HelpAge International. 2002c. *Participatory research with older people*: *A resource book.* London: HAI.

HelpAge International. 2003a. *Forgotten families. Older people as carers of orphans and vulnerable children.* Policy report. London: HAI.

HelpAge International. 2003b. Raising the issues of rights in Africa. *Ageing and Development.* 14: 6-7.

HelpAge International. 2004a. Last in the queue for treatment? *Ageing and Development*. 16: 9.

HelpAge International. 2004b. *Age and security: how social pensions can deliver effective aid to poor older people and their families*. London: HAI.

HelpAge International. 2004c. Ageing in Africa. Older people must be included in the fight against HIV/AIDS. *Ageways* 7. London. HAI.

HelpAge International. n.d. *Ageing issues in Africa*: *A summary report*. London: HAI.

HelpAge International. 2005a. Isolation in Darfur: Situation analysis report. *Ageing and Development.* 8:1. London. HAI.

HelpAge International. 2005b. Ageing in Africa. Leading global action on ageing. *Ageing and Development.* 23: 8. London. HAI.

HelpAge International**.** 2005c. Older people must be included in the fight against HIV/AIDS. *Ageways* . 40. London. HAI.

HelpAge International (HAI), 2006a. Older women lead response to HIV/AIDS. Available online: www.helpage.org/News/Latestnews/@27680. [2006, April 10].

HelpAge International (HAI), 2006b. *Practical issues in ageing and development, Ageways* (67). London. HAI.

HelpAge International. 2007. News and analysis of issues affecting the lives of older people. *Ageing and Development.* 21: 1-9.

HelpAge International. 2008a. Practical issues in ageing and development. How pensions reduce poverty. *Ageways.* 70: 4-6.

HelpAge International. 2008b. Age demands action; exploding the myth about older persons. *Ageing in Africa*. 32. London. HAI.

HelpAge, 2008c. Social pensions in South Africa. Available: http://www.helpage.org/Researchandpolicy/Socialprotection/PensionWatch/SouthAfrica [2009, September 14].

HelpAge Kenya. 2001. *The impact of HIV/AIDS on older people.* Workshop on HIV/AIDS report back. Nairobi: HelpAge Kenya.

HelpAge Kenya. 2002. *Feasibility study on viable income generating activities for older persons taking care of HIV/AIDS orphans conducted in Ahero, Nyando District Kenya.* Nairobi: HelpAge Kenya.

HelpAge Kenya. 2003. *Report of analysis of communication opportunities for older persons in Kenya*. *An audit phase of older citizen's monitoring project. Nairobi*: HelpAge Kenya.

HelpAge Sudan. 2003. *Older people as caregivers for HIV/AIDS orphans*. London: HelpAge.

Heckman, T., Kochman, A., Sikkema, K. et al. 1999. Depressive symptomatology, daily stressors, and ways of coping among middle age and older adults living with HIV disease. *Journal of Mental Health and Aging*. 5: 311-322.

Heslop, A., & Gorman, M. 2002. *Chronic poverty and older people in the developing World*. Chronic Poverty Research Centre Working Paper no 10. London: HAI.

Heywood, M. 1999. The AIDS epidemic in Africa: Openness and human rights. *SAFAIDS NEWs*. 7(1): 2-7.

Hill, R. 1994. *Families under stress*: *Adjustment to the crises of war separation and reunion*. New York. Harper & Brother.

Hinkle, K.L. 1991. A literature review: HIV seropositivity in the elderly. *Journal of Gerontology Nursing*. 17(10): 12-17.

Hoffman, J. 2004. *A post-modern exploration of intergenerational practices in Africa: a framework towards programming*. Paper presented in the African Conference on Ageing. Johannesburg, August 18-20.

Holmshaw, M. 1992. When will they ever learn…? *Current AIDS Literature*. 5(5): 149-150.

Homans, G.C. 1958. Social behaviour as exchange. *American Journal of Sociology*, 63(6):597-606.

Homsy, R. 1997. Involving traditional healers in AIDS education and counselling in sub-Saharan Africa: A review. *AIDS*. 11: 217-225.

Horizons. 2003. *The involvement of people living with HIV/AIDS, in Community-based Prevention, Care and Support Programmes in Developing Countries*: A multi-country Diagnostic Study.

Horizons. 2004a. *Expanding care and support in South India: Scaling up YRG care's patient – centered approach*. International HIV/AIDS Alliance Horizons Programme. Final Report. Washington DC**.**

Horizons. 2004b. *'Our hearts are willing, but …' Challenges of elderly caregivers in rural Kenya*. Research update. Washington, D.C.: USAID.

Horizons. 2005. *Providing Psychosocial Support to AIDS affected Children. Operations research informs programmes in Zimbabwe and Rwanda*. Research Report. Washington DC.

Horizons. 2006. *Strengthening HIV service delivery. Studies focus on care and treatment in India, Kenya and South Africa*. Horizons Report. Available: www.popcouncil.org/pfs/horizons/sacssymp.pdf [2006, July 7].

Horizons. 2007. Closer to home. Community-based activities complement PMTCT programmes in Kenya. Horizons Report. Washington DC.

Hosegood, V., Preston-White, E., Busza, J et al., 2007. Revealing the full extent of households' experiences of HIV and AIDS in rural South Africa. *Soc Sci Med,* 65(6):1249-59.

House, E.R. 1994. Integrating the quantitative and qualitative. *New Directions for Programme Evaluation*. 61: 13-23.

Household, C. 2009. *Message from the head of department to staff*. Official news letter of the Western Cape Department of Health. September pp. 3.

Howe, K.R. 1988. Against the quantitative-qualitative incompatability thesis or dogmas die hard. *Educational Researcher*. 17: 10-16.

Huber, B. 2004. Opening address. African Conference on Ageing. Johannesburg, August 18-20.

Hudelson, P.M. 1996. *Qualitative research for health programmes*. Geneva: WHO.

Human Development Report. 2000. *The political economy of transformation and human development. South Africa*. Available: www.undp.org.za/sahdr2000/hdr.chapter%20. [2008, February 7].

Human Development Report. 2007/08. *Country fact sheet*. Mbabane, Swaziland.

Humm, M. 1990. *The dictionary of feminist theory*. Columbus: Ohio State University Press.

Hunter, S.S. 1990. Orphans as a window on the AIDS epidemic in Sub-Saharan Africa: initial results and implications of a study in Uganda. *Social Science & Medicine*. 31(6): 681-690.

Human Rights Watch Kenya. 2005. *Country summary report*. Nairobi: KHRW

International AIDS Vaccine Initiative. 2003. *Report on the global AIDS epidemic*. 4th global report. Geneva: UNAIDS.

International HIV/AIDS Alliance. 2002. *Participation in the Global Fund: a review paper*. London. Available: www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Policy/NGO%20Participation.pdf [2006, October 29].

International HIV/AIDS Alliance. 2003. *Building blocks: Africa wide briefing notes -- psychosocial support.* Brighton : International HIV/AIDS Alliance.

International Labour Organisation. 1942. *Approaches to social security*. Montreal: ILO.
The ANNALS of the American Academy of Political and Social Science. 1942; 222: 237

Jackson, H. 2002. *AIDS Africa: Continent in crisis*. Harare: SAFAIDS.

Jackson, H., & Anderson, S. 2001. Home care for people with AIDS. In *HIV/AIDS prevention and care in resource constrained settings: A handbook for the design and management of programmes*. Lamptey, P.R., & Gayle, H.D. Eds. Arlington, VA: Family Health International.

Jackson, H., & Kerkoven, R. 1995. Developing AIDS care in Zimbabwe: a case for residential community centers? *AIDS Care*. 7(5): 663-673.

Jacoby, A. 1994. Felt versus enacted stigma: A concept revisited, evidence from a study of people with epilepsy in remission. *Social Science & Medicine*. 38(2): 269-274.

James, K. 2004. *HIV/AIDS and the changing role of the aged. Understanding the role, constraints and consequences for the elderly as providers of education to children orphaned by HIV/AIDS*. Paper presented in the international conference "Rapid ageing and the changing role of the elderly in African households" Johannesburg, 18-20 August**.**

Jamil, I., & Muriisa, R. 2004. *Building social capital in Uganda: the role of NGOs in mitigating HIV/AIDS challenges*. Paper presented in the conference of the International Society for Third Sector Research (ISTR), Toronto.

Janicki, M.P., & MacEchron, A.E. 1984. Residential, health, and social service needs of elderly developmentally disabled persons. *Gerontologist.* 24: 128-137.

Jayaraman, K.S. 1998. Indian state plans compulsory HIV testing, segregation and branding. *Nature Medicine*. 4(4): 378.

Jazdowska, N. 1992. *Elderly women caring for orphans and people with AIDS, Ward Six, Hurungwe District*. Harare, Zimbabwe: HelpAge Zimbabwe.

Jedlovsky, V., & Fleischman J.K. 2000. Pneumocytis carinii pneumonia as the first presentation of HIV infection in patients older than fifty. *AIDS Patient Care*. Jamaica: Mount Sinai Services, Queens Hospital Center.

Jewkes, R., Abrahams., N., & Mvo, Z. 1998. Why do nurses abuse patients? Reflections from South African obstetric services. *Social Science & Medicine*. 47(11): 1781-1795.

Jick, T.D. 1979. Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly*, 24: 602-611.

Johansson, C. 2008. Human development report shocks South Africa. Available: http://www.afrol.com/articles/16932. [2008, March 25].

Johnson, B.K. 1996. Older adults and sexuality: a multidimensional perspective. *Gerontological Nursing*. 22: 6-15.

Johnson, S., Shierhout, G., Steinberg, M. et al. 2002. AIDS in the household. In *South African Health Review.* Ijumba, P., A. Ntuli, & P. Barron, Eds. Durban: Health Systems Trust, 203 – 216.

Johnston, A.G. 2001. *Twelve key messages on HIV/AIDS. A briefing paper to US Ambassadors in Africa*. Report prepared by the Policy Project for the US Agency for International Development. Washington D.C.

Jones, S. 1996. Individual mobility and domestic fluidity. In *Marriage and family life in South Africa: research priorities*. Pretoria: Human Sciences Research Council.

Joubert, J.D., Bradshaw, D. 2000. *Burden of disease in older persons in South Africa*. Parow Valley: South Africa. Medical Research Council, Burden of Disease Research Unit.

Joubert, J., & Bradshaw, D. 2004. Health of older persons: Leading single causes of death in persons 60+, 2000. *SA Health Review*, Health Systems Trust. 147– 162. Available: www.//search.sabinet.co.za/WebZ/images/ejour/healthr/healthr_2003_a11.pdf:sessionid=0:bad=http://search.sabinet.co.za/ejour/ejour_badsearch.html:portal=ejournal:[2007, October 22].

Joubert, J., & Bradshaw, D. 2005. Population ageing and health challenges in South Africa. In *Chronic diseases of lifestyle in South Africa since 1995-2005*. Technical Report. Parow Valley: SA Medical Research Council.

Joubert, J.D., Swart, D., & Reddy, P. 1998. Knowledge, perceptions and needs of older persons with reference to 1999, the International Year of Older Persons: A qualitative study in the Eastern Cape. Unpublished. Parow Valley: SA Medical Research Council.

Joubert, J.D., Reddy, P., & Bryan, W. 2002. Informal care in South Africa: A carer perspective. Final report. Parow Valley: SA Medical Research Council.

Kahana, E., & Kahana, B. 2001. Successful aging among people with HIV/AIDS. *Journal of Clinical Epidemiology*. 52: S53-54.

Kaleeba, N., Kalibala, S., Kaseje, M. et al. 1997. Participatory evaluation of counseling, medical and social services of AIDS Support Organisation (TASO) in Uganda. *AIDS Care*. 9(1): 13-26.

Kaleeba, N., Ray, S., & Willmore, B. 1991. *We miss you all: AIDS in the family*. Harare: Women and AIDS Support Network.

Kart, C. 1981. Experiencing symptoms: Attributions and misattributions of illness among the aged. In *Elderly patients and their doctors*. Huang, M., Ed. New York: Sage. 70-78.

Kasternbaum, R. 1993. *Encyclopeadia of adult development*. Arizona, Orynx Press.

Katzenellenbogen, J., Joubert, G., & Yach, D. 1991. *Introductory manual for Epidemiology in South Africa*. Parow Valley: SA Medical Research Council.

Kelley, H.H., & Thibault, W.A. 1978. *Interpersonal relations: A theory of interdependence*. New York: John Wiley.

Kelley, S.J. 1993. Caregiver stress in grandparents raising grandchildren. *IMAGE: Journal of Nursing Scholarship*. 25: 331-337.

Kent, M.M., & Haub, C. 2005. Global demographic divide, *Population Bulletin*. 60(4). Washington, D.C.: Population Reference Bureau.

Kenya National HIV/AIDS Strategic Plan. 2005/6 - 2009/10. *A call to action*. Nairobi: National AIDS Control Council.

Kerlinger, F. 1964. *Foundations of behavioral research*. 3rd ed. New York: Holt, Rinehart & Winston.

Kespichyawattana, J., & Van Landingham, M. 2003. Effects of co-residence and caregiving on health of Thai parents of adult children with AIDS. *Journal of Nursing Scholarship*, 35(3): 217-224.

Ketetu. n.d. Girls' and Women's Education in Kenya. Nairobi. UNESCO. Available: http://www.education.nairobi-unesco.org/index.php?option=com_content&task=view&id=799&Itemid=56 [23, October 2008]

Kiely, J., & Hodgson, G. 1990. Stress in prison service: The benefits of exercise programmes. *Human Relations*. 43: 551-72.

Kish, L. 1965. *Survey sampling*, New York: John Wiley.

Kish, L. 1987. *Statistical design for research*, New York: John Wiley.

Kimuna, S.R. 2004. *Living arrangements of older adults in Zimbabwe: Their socioeconomic and socio-demographic conditions*. Presentation in the African Conference on Ageing. Johannesburg, August 18-20.

Kinsella, K., & Ferreira, M. 1997. *Aging trends*: *South Africa*. Washington, D.C.: U.S. Bureau of Census.

Kinsella, K., & Phillips, D. 2005. The global ageing: The challenge of success. *Population Bulletin*. 60(1): 6- 42.

Kirby, D. 2002. The impact of schools and school programmes upon adolescent sexual behaviour. Journal of Sex Research. 39: 27-33.

Knodel, J. 2005. Researching the impact of the AIDS epidemic on older-age parents in Africa: Lessons from studies in Thailand. Journal of the *British Society of Gerontology*. 15(2): 16-22.

Knodel, J., & Im-em, W. 2004. The economic consequences of parents of losing an adult child to AIDS: Evidence from Thailand. *Social Science & Medicine*. 59(5): 987-1001.

Knodel, J., & Saengtienchai, S. 2001. *Parents providing care to adult sons and daughters in Thailand. UNAIDS case study*. Geneva: UNAIDS.

Knodel, J., & Van Landingham, M. 2000. Children and older persons: AIDS' unseen victims. *American Journal of Public Health*. 90(7): 1024-1025.

Knodel, J., Watkins, S., & Van Landingham, M. 2002. *AIDS and older persons: An international perspective*. Population Studies Report No. 02-495. Ann Arbor, MI: Population Studies Center, University of Michigan.

Knodel, J., Watkins, S., & Van Landingham, M. 2003. AIDS and older persons: an international perspective. *Journal of Acquired Immune Deficiency Syndrome*. 33(2): S153-65.

Knodel, J., Zimmer, Z., Sovan-Kim, K. et al. 2006. *The impact of AIDS on older-age parents in Cambodia*. Report 06-594. Ann Arbor: Population Studies Center, University of Michigan.

Kondel-Lule, J.K., Sewankambo, N., Mawer, et al. 1996. *The impact of AIDS on families in Rakai District, Uganda*. Paper presented in the XIth International Conference on AIDS, Vancouver.

Kok, P., & Collinson, M. 2006. *Migration and urbanization in South Africa*. Human Sciences Research Council. Pretoria.

Kongsin, S., & Watts, C.H. 2000. *Conducting a household survey on economic impact of chronic HIV/AIDS morbidity in rural Thailand. Methodological issues*. Paper presented in the AIDS and Economics Symposium, Durban, July, 7-8.

Kopelman, L.M. 1988. The punishment concept of disease. In C. Pierce and D. Van de Veer (Eds.). AIDS: Ethics and public policy (pp. 49-55). Belmont, CA: Wordsworth Publishers.

K'Oyugi, B., & Muita, J. 2002. The impact of a growing HIV/AIDS epidemic on Kenyan children: AIDS public policy and child well-being. Available: www.unicef-irf.org/research/ESP/AIDS/chapter3.pdf. [2009, May 24].

Krippendorf, K. 2004. *Content analysis: An introduction to its methodology*. 2nd ed. Thousand Oaks, CA: Sage.

Kumar, K. 1986. *Conducting key informant interviews in developing countries*. AID Programme Design and Evaluation Methodology Report No.13. Washington, D.C.: Agency for International Development.

Kutz, S.J. 2004. Social capital and health. *British Medical Bulletin*, 69: 61–73.

Kyobutungi, C., Ezeh, A., & Falkingham, J. 2009. HIV/AIDS and the health of older people in the slums of Nairobi, Kenya: results from a cross-sectional survey. *Public Health*, 9: 153.

Lang, S.S. 2005. In Africa, children as young as 9 are heading households and turning to other children for help. Chronicles, University of Cornell. Available: http://www.news.cornell.edu/stories/Nov05/africa.orphan.heads.ssl.html. [2008, November 29].

Last, J.M. 1988. *Ethics and Epidemiology*. World Health Report. Geneva: WHO. 22-24.

Lauer, J. 1999. The ageing face of AIDS. Jacksonville Medicine. *American Journal of Geriatrics and Social Sciences*. 17(9):39-42.

Lee, C.C., Leo, Y.S., Snodgras, I. et al. 1997. The demography, clinical manifestations and natural history of human immunodeficiency virus (HIV) in infection in an older population in Singapore. *Journal of Association of Nurses in AIDS Care*, 20: 3.

Lee, G.R. 1980. Kinship in the seventies: a decade review of research and theory. *Journal of Marriage and the Family*. 42: 923-934.

Legido-Quigley, H. 2003. *The South African old age pension: Exploring the role on poverty alleviation in households affected by HIV/AIDS*. Paper presented in the 4th International Research Conference on Social Security Antwerp, Belgium 5-7 May, 5-7.

Lenton, C., Hawkins, K., & Jani, R. 2003. *Evaluation of targeted interventions in reduction of HIV transmission in five states in India*. London: Department of International Development (DFID).

Lesar, S., Gerber, M., & Semmel, M. 1995. HIV infection in children: Family stress, social support, and adaptation. *Exceptional Children*. 62: 224-236.

Lesthaeghe, R. 1983. A century of demographic and culture in Western Europe: an explanation of underlying dimensions. *Population and Development Review*. 9: 411-435.

Lesotho Council of NGOs. 2006. Human rights violations under scrutiny in Lesotho. Available: www.lecongo.org.ls/newsletters/HR_Violation_Scrutiny.php [2008, February 1].

Levinson, B.A. 1994. *The cultural production of the educated person: critical ethnographies*. New York: Albany.

Lerman, H. 1990. *Feminist ethics in psychotherapy*. New York: Springer.

Lieberman, R. 2000. HIV in older Americans: an epidemiological perspective. *Journal of Midwifery and Women's Health*. 45(2):176-182.

Liese, B., Blanchet, N., & Dussault, G. 2003. *The human resource crisis in health services in sub-Sahara Africa*. Washington, D.C.: World Bank.

Linsk, H. 1994. HIV and the elderly. HIV/AIDS. *Families in Society*. 75: 362-372.

Lisk, F. 2002. *Labour market and employment implications of HIV/AIDS.* Working Paper 1. Geneva: ILO Programme on HIV/AIDS and the World of Work.

Lohmann, R. A. 1992. *The commons: new perspectives on non-profit organizations and voluntary action*. CA: Jossey-Bass.

Luggen, A.S. 1996. AIDS in the older adult. In *Geriatric Nursing core curriculum for gerontological nursing*. Luggen, A.S., Ed. St. Louis: Mosby.

Lund, F. 1999. Understanding South African social security through recent household surveys: New opportunities and continuing gaps. *Development Southern Africa*. 16(1): 55-57.

Lurie, M.N., Harrison, A., & Wilkinson, D. et al. 1997. Circular migration and sexual networking in rural KwaZulu-Natal: implications for the spread of HIV and other sexually transmitted diseases. *Health in Transition Review,* 17(3): 17-27.

Lurie, M.N., Williams, B.G., Zuma K. et al. 2003. The impact of migration on HIV-1 transmission in South Africa: A study of migrant and non-migrant men and their partners. *Sexually Transmitted Diseases*. 30: 149-156.

Lusk, D., Huffman, S.L., & O' Gara, C. 2004. Assessment and improvement of care for AIDS-affected children under age 5. Available: www.pronutrition.org/pubview.php/54 [2005, October 30].

Maartens, G. 2002. HIV/AIDS in South Africa. In *Prevention of opportunistic infections in adults*. Abdool-Karim, S & Q. Abdool-Karim. Eds. New York: Cambridge University Press. 454-462.

MacNeil, J.M. & Anderson, S. 1998. "Beyond the dichotomy: linking HIV prevention with care." *AIDS Care*. 12(2): S19-26.

Mahendra, V.S., Panda, A.K., & Bajaj S. 2002. Factors affecting health seeking behavior of People Living with HIV/AIDS (PLHA) in New Delhi, India: Results of a qualitative study. International Conference on AIDS. Jul 7-12; 14.

Maher, J. 2006. HIV and AIDS and older people in developing countries. *Global Ageing*. 4(2): 14-32.

Maitse, T. 2001. *Racism, xenophobia and gender in the context of the world.* Paper presented in the World Conference on Gender and Racism and Related Intolerances, Durban, South Africa.

Makiwane, M., Schneider, M., & Gopane, M. 2004. *Experiences and needs of older persons in Mpumalanga*. Report written for the Human Sciences Research Council and Department of Social Services, Mpumalanga.

Makubalo, L., Netshidzivhani, P., Mahlasela, L. et al. 2004. *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa*. Pretoria: Department of Health.

Malcolm, A., Aggleton, P., Bronman, M. et al. 1998. HIV related stigmatization and discrimination: Its forms and contexts. *Critical Public Health*. 8(4): 321-333.

Malone, M.A. 1998. HIV-positive women over fifty: How they cope. *AIDS Patient Care and STDs*. 12(8): 639.

Maluwa, M. 2000. *Background note: HIV/AIDS and human rights*. Presentation in the Regional NORAD/SIDA Meeting on Strengthening the Integration of HIV/AIDS into Development Cooperation. Zomba, Malawi, November 16-17.

Mamdhani, M. 2001. *When victims become killers. Colonialism, nativism, and the genocide in Rwanda*. Cape Town. David Philip.

Manby, B. 2004. The African Union, NEPAD, and human rights: The missing agenda. *Human Rights Quarterly*. 26(4): 983-1027.

Mandela, N. 2000. Closing address by former President. AIDS *Bulletin*, 99(3): 3-11.

Mann, J.M . 1989. *AIDS:* A worldwide pandemic. In *Current topics of AIDS,* 2. Gottlieb, M.S., D.J Jeffries, D, Mildivan, Pinching, A.J., & T.C Quinn, Eds. Geneva: John Wiley.

Marcfarlane, M. n.d. Doctors not enough in South Africa. Available: www.thetidenews.com/article.aspx?qrDate. [2006, April 19].

Marcoux, A. 2001. *Ageing rural populations in the developing countries: patterns, causes and implications.* Paper presented in the United Nations' International Conference on Ageing Populations in the Context of the Family, Kitakyushu, Ageing and the family, New York.

Mason, A. 2001. Aging population tied to shrinking work force, slower economic growth. *East-West Center Observer*. 5(1): 2-5.

Masulit, S.P. 1998. Assessment of a community-based health programme for the elderly: implications for future initiatives. Unpublished MSc dissertation. Philippines: De La Salle University.

Mathews, C. 2005. Reducing sexual risk behaviours: Theory and research, successes and challenges. In *HIV/AIDS in South Africa.* A, Karim, & Q. Karim, Eds. New York: Cambridge University Press. 143-163.

Matshalaga, R.N., & Powell, G. 2002. Mass orphanhood in the era of HIV/AIDS. Bold support for alleviation of poverty and education may avert a social disaster. *British Medical Journal.* 324: 185-86.

May, J. 2003. *Chronic poverty and older people in South Africa*. Durban: University of KwaZulu-Natal.

Mayan, M.J. 2001. *An introduction to qualitative methods*: *A training module for students and professionals*. Alberta, Canada: International Institute for Qualitative Methodology.

Mazhani, L., Sekgoma, B., & Mokopakgosi, O. 2000. Report of mid-term review of the prevention of MTCT programme of Botswana Ministry of Health and UNICEF. Gaberone: Ministry of Health.

Mba, C.J. 2004. *Population ageing and poverty in rural Ghana*. Paper presented in the African Conference on Ageing, Johannesburg, August 18–20.

Mbali, M. 2002. Mbeki's denialism and the ghosts of apartheid and colonialism for post Apartheid AIDS policy-making. Public Health Journal Club seminar paper, University of Natal, Durban, May 3.

Mbazira, C. 2006. *Realising socio-economic rights in the South African Constitution: The obligations of local government. A guide for municipalities*. Cape Town: Community Law Centre, University of the Western Cape.

Mbola, B. 2008. Social grant spending increased. Midterm Budget speech by minister of finance, 2008. *BuaNews*, 21 February: 2

McCoy, D., & Engelbrecht, B. 1999. Establishing the District Health System. *South African Health Review*. Durban: Health Systems Trust.

Mckenry, P. & Price, S. 1994. *Families and changes: Coping with stressful events*. Thousand Oaks, CA: Sage.

Mcqueen, D. 1992. Understanding sexual behaviour. *AIDS.* 6: 329-330.

Meadows, J., Le-Marechal, K., & Catalan, J. 1999-2001. The burden of care: the impact of HIV-associated dementia on caregivers. *AIDS-Patient-Care-STDs.*13(1): 47-56.

Mercy, J.A. 1993. Public Health policy for preventing violence. *Health Affairs.* 12: 7-29.

Merli, G., Palloni, A. 2004. The HIV/AIDS epidemic, kin relations, living arrangements and the elderly in South Africa, CDE working paper. University of Winsconsin.

Merriam, S.B. 1991. *Case study research in education.* San Francisco: Jossey-Bass.

Messkob, M. 1999. Crisis of ageing in less developed countries: Too much consumption or too little production? *Development and Change*. 5(1): 2-5.

Meyer, S. 2002. *The influence of parental incomes on children's outcomes*. New Zealand**:** Ministry of Social Development.

Meyers, D.T. 2000. Feminism and women's autonomy: The challenge of female genital cutting. *Metaphilosophy*, 31(5): 469-491.

Michael, A. 2007. *Webster's new world College Dictionary*. New York. John Wiley.

Miles, M., & Huberman, A.M. 1984. *Qualitative data analysis: A source book of new methods.* London: Sage.

Miller, D. 2000. *Dying to care? Work, stress and burnout in HIV/AIDS*. London and New York: Routledge.

Minkler, M., Roe., K.M., & Price, M. 1992. The physical and emotional health of grandmothers raising grandchildren in the crack cocaine epidemic. *Gerontologist.* 32: 752-761.

Minkler, M., & Roe, K.M. 1993. *Grandmothers as caregivers: Raising children of the crack cocaine epidemic*. Newbury Park, CA: Sage.

Mishler, E. 1986. *Research interviewing: context and narrative*. Cambridge, MA: Harvard University Press.

Mitchell, M., & Jolly, J. 1996. *Research design explained.* 3rd ed. New York: Harcourt Brace College. USA.

Moderator. 2008. Minister of Health and Others vs Treatment Action Campaign and Others. Available: http://www.constitutionalcourt.org.za/uhtbin/hyperion-image/S-CCT8-02. [2008, December 28].

Mohaty, C.T. 2003. *Feminism without borders: Decolonizing theory, practicing solidarity*. Durham, NC. Duke University Press.

Molm, L.D. 2001. Theories of social exchange network. In *Handbook of social theory*. Ritzer, G., & B, Smart, Eds. London: Sage, pp. 260-272.

Mϕller, V., & Ferreira, M. 2003. Getting by… Benefits of non-contributory pension income for older South African households. Cape Town: Institute of Ageing in Africa, University of Cape Town.

Mϕller, V., & Sotshongaye, A. 1996. My family eats this money too: pension sharing and self-respect among Zulu grandmothers. *South African Journal of Gerontology*. 5(2): 9-19.

Monasch, R., & Clark, F. 2004. Grandparents' growing role as carers. *Ageing and Development*, London: HAI. Available: http://www.avert.org/older-people.htm . [2008, October 26].

Morgan, D. 1998. Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research*. 8(3): 362-376.

Morse, J.M. 1991. Approaches to quantitative-qualitative methodological triangulation. *Nursing Research*. 4(1): 120-123.

Msimang, S. 2003. UNIFEM Cape Town Consultation, in partnership with the Positive Women's Network, and the Youth Against AIDS Network, May 2003 Cape Town.

Mtei, L.N., & Pallagyo, K.P. 2001. HIV infection in elderly medical patients. *East African Medical Journal.* 78(3): 144-147.

Morton, L.R. 2002. Building local knowledge for developing health policy through key informant Interviews. *Journal of Extension.* 40(1): 1-9.

Moustakas, C. 1994. *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Mpanju-Shumbusho, W. 2003. Building capacity and community resilience to HIV. Presentation in the Planning Workshop for Increasing Access to Care and Treatment for PLWHA, Harare, June, 7-10.

Mupedziswa, R. 1997. AIDS and older Zimbabweans: Who will care for the carers? *South African Journal of Gerontology.* 6(2): 9-12.

Mustafa, K. 2004. Policy workshop Opening statement on behalf of the United Nations Namibia Country Team. United Nations Department of Economic and Social Affairs, Windhoek, January, 28-30.

Mwagi, F.W. 1994. Care for HIV positive orphans at Nyumbani hospice in Kenya. International Conference. *AIDS*, 10(2): 400.

Mwape, G. 2003. *The role of older people as carers of orphans and vulnerable children in Katuba area of Chilombo district, Zambia*. London: International HIV/AIDS Alliance.

Nampanya-Serpell, N. 2000. *Social and economic risk factors for HIV/AIDS-affected families in Zambia*. Paper presented in the AIDS and Economics Symposium, Durban, July, 7-8.

Narain, J.P., Chela, C., & Van Praag, E. 1998. *Planning and implementing HIV/AIDS care programmes*: *A step by step approach*: WHO. Regional Office for South-East Asia.

Nattras, N. 2005. Trading off income and health?: AIDS and the disability grant in South Africa. *Journal for Social Policy*. 35(1): 3-19.

Nesbary, D.K. 2000. *Survey research and the world wide web*. Boston: Allyn & Bacon.

Neugarten, B. 1971. Grow old along with me! The best is yet to be. *Psychology Today*. 5: 45-48 & 79-81.

Newman, I., & Benz, C.R. 1998. *Qualitative-quantitative research methodology*: *Exploring the interactive continuum*. Carbondale: Southern Illinois University Press.

New Partnership for Africa's Development (NEPAD). 2001. New Partnership for Africa's Development document. Available: www.dfa.gov.za/au.nepadbrief.htm, [2008, April 6].

Ngalula, J., Urassa, M., Mwaluko. G. et al. 2001. Health service use and household expenditure during terminal illness due to AIDS in rural Tanzania. *Tropical Medicine & International Health*. 7(10): 873-877.

Nhongo, T. 2003. Speech at the launch of the African Union Policy Framework and Plan of Action on Ageing. Addis Ababa, Ethiopia.

Nhongo, T. 2004. *Rapid ageing and the changing role of the elderly in African households*. Paper presented in the African Conference on Ageing. Johannesburg. August, 18-20.

Niehaus, I. 2001. *Witchcraft, power and politics: Exploring the occult in the South African Lowveld*. London: Pluto Press.

Nightingale, D.S., & Rossman, S.B. 1994. Managing field data collection from start to finish. In *Handbook of practical programme evaluation*. Wholey, J.S., H.P. Hatry, & K.E. Newcomer, Eds. San Fransisco: Jossey-Bass.

NMG-Levy Consultants and Actuaries. 2002. *AIDS: The private sector challenge*. Cape Town.

Nokes, K.L., Rivero-Mendez, M., Valencial, C.P. et al. 2006. Socio-demographic and other characteristics in persons 50 years and older with HIV/AIDS in five countries. Montreal: International Federation on Ageing. 5-13.

Noumbissi, A. 2004. *Poverty among the elderly in South Africa*. Paper presented in the African conference on Ageing. Johannesburg, August. 18-20.

Nsutebu, F.E. 2001. Scaling up HIV/AIDS and TB home-based care: Lessons from Zambia. *Health Policy Plan*, 16(3): 240-247.

Ntozi, J., & Nakayiwa, S. 1999. AIDS in Uganda: How has the household coped with the epidemic? In *The continuing HIV/AIDS epidemic in Africa: Response and coping strategies.*

Ntozi, P.M., Ahimbisibwe, F.E., & Odwee, J.O et al., 1999. *Orphan care: The role of the extended family in northern Uganda*. *The continuing African HIV/AIDS epidemic, AIDS Care,* 22: 225-236.

Orubuloye, I.O., J.C. Caldwell, & J. Ntozi, Eds. Canberra: Australian National University Health Transition Centre.

Nusberg, C. 2006. Age, ageism, and HIV/AIDS. *Global Ageing: Issues and Actions.* 4(2): 2-3.

Nxusani, N.V. 2004. Late life migration and adjustment of older persons: between the Eastern Cape and Western Cape provinces in South Africa. In Untold stories: Giving voice to the lives of older persons in new South Africa. An anthology. Ferreira, M., & Van Dongen, Eds. Cape Town: Institute of Ageing in Africa, University of Cape Town.

Nyblade, L. 2003. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. Washington, D.C.: International Centre for Research on Women.

Nzimande, S.V. 1996. Family structure and support systems in black communities. In *Marriage and family in South Africa, family structure and support systems*. Pretoria: Human Sciences Research Council.

Office of Population Censuses and Surveys (OPCS). 1989. *General household survey*, 1986. London: HMSO.

Ohuche, N.M., & Littrell, J.M. 1989. Igbo students attitudes toward supporting aged parents. *International Journal on Ageing and Human Development*. 29(4): 259-267.

Ogden, J., Esim, S., & Grown, C. 2004. *Expanding the care continuum for HIV/AIDS: Bringing carers into focus*. Horizon Report. Washington, D.C.: International Center for Research on Women.

Okoye, U.O. 2004. *The erosion of traditional forms of care for the elderly and its implication for the elderly in Nigeria.* Paper presented in the Africa Conference on Ageing. Johannesburg. August 18-20.

Oleja, J.M. 1999. Assessing community attitude towards home based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*. 24(3): 187-199.

Olshansky, S. 1962. Chronic sorrow: A response to having a mentally defective child. *Social Casework*. 63: 190-193.

Onyx, J., & Leonard, R. 2002. *Transforming civil society, citizenship and governance: The third sector in an era of global (dis) order*. Paper presented in the 5th International Conference on governance. Cape Town. July 7-10.

Organisation of African Union (OAU). 1980. *Lagos Plan of Action for the Economic Development of Africa* 1980-2000. Geneva. Institute of Labour Studies, 3, 7.

Organisation of African Union (OAU). 1981. African (Banjul) Charter on Human and People's Rights, 1981 Declaration on Human and People's Rights. Nairobi. Available: www.preventgbvafrica.org/content/african-banjul-charter-human-and-peoples-rights-1981-declaration-human-and-peopl.. [2007, September 21].

Orner, P. 2006. Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*. 18(3): 236-240.

Osborne, C. 1996. HIV/AIDS in resource-poor settings: comprehensive care across a continuum. *AIDS*. 10(3): 61-67.

PAHO/WHO. 2000. *Building blocks: Comprehensive care guidelines for persons living with HIV/AIDS. A summary report*. Available: http://www.paho.org/english/hcp/hca/BuildingBlocks.pdf [2006, July 23].

Page, S.L.J. 2000. *Longevity in HIV+ mothers: the need to promote good health, household food security and economic empowerment to ensure family survival in Southern Africa*. Paper presented in the UN Expert Group Meeting on the HIV/AIDS Pandemic and its Gender Implications, Windhoek. November 13-17.

Palloni A., & Lee Y. 1992. Some aspects of the social context of HIV and its effects on women, children, and families. *Population Bulletin of the United Nations.* 33: 64–87.

PANOS. 1990. *Triple jeopardy: Women and AIDS*. London: PANOS Institute.

Parker, W., & Kelly, K. 2000. Communities of practice. Contextual mediators of youth response to HIV/AIDS. Sentinel site monitoring and evaluation project. Centre for AIDS Development, Research and Evaluation. Available: www.cadre.org.za. [2006, January 4].

Parker, R.G., Eason, D., & Klein, C.H. 2000. Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS*. 14(1): 22-32.

Pathfinder International. n.d. *Responding to HIV/AIDS. Community Home Based Care*. A Fact Sheet.

Programme for Appropriate Technology in Health (PATH). 1994. A response to recent questions about latex condom effectiveness in preventing sexual transmission of the AIDS virus. Condoms: How effective are they? *SAFAIDS News*. 3(4):14.

Patton, M.Q. 1990. *Qualitative evaluation and research methods.* 2nd ed. London: Sage.

Peltzer, K., Mngqundaniso, C.N., & Petros, S.G. 2005. A controlled study of an HIV/AIDS/STI/TB intervention with traditional healers in KwaZulu-Natal, South Africa. *AIDS and Behavior*. 10(6): 83-690.

Peltzer, K., Phaswana-Mafuya, N., Petros, S.G. et al. n.d. Health care quality assurance: Primary Health Care service delivery in South Africa. Report prepared for the European Union Department of Health (South Africa).

Perlman, M. 1988. The fine line between knowledge and terror. *The Weekly Mail*, December 10-11. 15-22.

Petros, S.G., Arhihenbua, C., & Ramlagan, S. et al. 2005. HIV/AIDS "othering" in South Africa: the blame goes on. *Culture, Health & Sexuality*. 8(1): 67-77.

Phaswana-Mafuya, N., Petros, S.G., Peltzer. K. et al. 2008. Health care quality assurance: Primary Health Care service delivery in South Africa. *International Journal of Health Care Quality Assurance*. 21(6): 611-624.

Phiri, S.N., Foster, G., & Nzima, M. 2001. *A study to explore ways to scale up effective, sustainable community mobilization interventions to mitigate the impact of HIV/AIDS on children and families*. Paper prepared for the displace Children and Orphans Fund of USAID. March 21.

Phororo, H. 2000. *Why the private sector should be concerned about HIV/AIDS*. Occasional Paper 1. Windhoek: Hans Seidal Foundation of Namibia.

Pillay, Y., Mzimba, M., & Barron, P. 1998. *Handbook for district managers*. Pretoria: Department of Health (South Africa).

Pillay, Y., McCoy, D., & Asia, B. 2001. *The District Health System in South Africa: Progress made and next steps*. Available: http://www.doh.gov.za/docs/policy/dhsystem.html [2005, June 18].

Pisani, E. 1999. AIDS into the 21st Century: Some critical consideration. *SAfAIDS News*. 7(4): 2-10.

Poggenpoel, M. 1998. Data analysis in qualitative research. In *Research at grassroots. A primer for the caring professions*. De Vos, A.S., Ed. Pretoria: van Schaik. 334-353.

Population Council. 2000. Syndromic method poor at detecting STIs in women. *Population Briefs*. 6(1): 4.

Porter, K., & Zaba, B. 2004. The empirical evidence for the impact of HIV on adult mortality in the developing world: data from serological studies. *AIDS*. 18 (2): S9-S17.

Portney, L.G., & Walkins, M.R. 1993. *Foundations of clinical research: Applications to practice*. East Norway, CT: Appleton & Lange.

Potter, J., & Wetherell, M. 1987. *Discourse and social psychology: beyond attitudes and behaviour*. London: Sage.

Poundstone, K.E., Strathdee, S.A., & Celentano, D.D. et al. 2004. The social epidemiology of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. *Epidemiologic Reviews*. 26: 22-35.

Prince, B., Kleintjies, S., & Cloete, A. et al. 2005. Contextualising gender mainstreaming. In *Gender Mainstreaming in HIV/AIDS*. Seminar Proceedings. 7th AIDS Impact conference. Cape Town. Human Sciences Research Council.

Procaare, H.C. 2001. Stigma and care: setting the scene. Available: www.old.healthnet.org/programs/procaare-hma/procaare.200109/msg00019.html. [2006, December 23].

Putnam, R.D. 1993. *Making democracy work*. Princeton, NJ: Princeton University Press.

Putzel, J. 2003. Institutionalizing an emergency response*: HIV/AIDS and governance in Uganda and Senegal*. A report submitted to the Department for International Development, UK, May.

Qwane, E. 2001. An analysis of reasons for wanting and not wanting to disclose HIV status. *South African AIDS information dissemination service News (SAfAIDS)*, 96(6): 280-282.

Rabelo, F.M. 2004. *The impact of ageing on the future of civil service*. Presentation in the Ad-hoc Expert Group Meeting "Unlocking the Human Potential for Public Sector Performance", Florence, May 6-8.

Rajan, S.I., Perera, M., & Begum, S. 2004. *Pensions and social security policies for elderly in South Asia*. Paper read in the African Conference on Ageing. Johannesburg, August18-20.

Ray, S., & Mataure, P. 2000. *The Mabvuku Hospice and Home Care Project Evaluation* 2000, Harare: Evaluation Report, SAfAIDS.

Rawlston, V. 2000. *The impact of social security on child poverty*. Special Research Report (SRR-01-2000) Washington, D.C.: National Urban League.

Rebouche', R. 2006. Labour, land and women's rights in Africa: Challenges for the New Protocol on the Rights of Women. *Harvard Human Journal*. 19.

Rees, M. 1989. Miners, refugees, soldiers at risk. *WorldAIDS*, 4(6).

Rehle, T.M. & Shisana, O. 2003. Epidemiological and demographic HIV/AIDS projections. *South Africa. African Journal of AIDS Research*. 2(1): 1-8.

Richardson, J. J. & Jordan, A. G. 1983. Overcrowded policymaking: Some British and European reflections. *Policy Sciences*. 15(3): 247-268.

Rifkin, S., & Walt, G. 1986. Why health improves: Defining the issues concerning comprehensive primary health care. *Social Science & Medicine*. 23: 559-566.

Robinson, C. 1993. *Real world research. A resource for social scientists and practitioner researchers*. Oxford: Blackwell.

Rose, M.A. 1995. Knowledge of human immunodeficiency virus and acquired immunodeficiency syndrome, perception of risk, and behaviours among older adults. *Holistic Nursing Practice*. 10(1): 10-17.

Rounds, K.A., Galinsky, M.J., & Stevens, L.S. 1991. Linking people with AIDS in rural communities: The telephone group. *Social Work*. 36(1): 195-207.

Rossman, G.B., & Rallis, S.E. 1998. *Learning in the field*: *An introduction to qualitative research*. Thousand Oaks, CA: Sage.

Rosnow, R., & Rosenthal, R. 1996. *Beginning behavioral research: A conceptual Primer*. 2nd ed. New Jersey: Prentice-Hall.

Rosser, S. 1991. AIDS and women: *AIDS Education and Prevention*, 3(3): 230-240.

Rowe, J.W., & Kahn, R.L. 1998. *Successful aging*: *The MacArthur Foundation Study*. New York. Pantheon.

Rubin, L.B. 1976. *Worlds of pain: Life in the working-class family*. New York: Basic Books.

Russell, M., & Schneider, H. 2000. *A rapid appraisal of community based HIV/AIDS care and support programmes in South Africa*. Durban: Health Systems Trust.

Saad, K., Hartman, J., Ballard, C. et al. 1995. Coping by the carers of dementia sufferers. *Age Aging*. 24: 495-498.

SAFAIDS. 2000. HIV/AIDS and development. *HIV/AIDS Fact Sheets*, 2. Harare.

SAFAIDS. 1995. Condoms: How effective are they? *SAfAIDS News*. 3(4):14.

Sagner, A. 2000. Ageing and social policy in South Africa: Historical perspectives with particular reference to the Eastern Cape. *Journal of Southern African Studies* 26(3): 523-553.

Sagner, A., & Mtati, R.Z. 1999. Politics of pension sharing in urban South Africa. *Ageing and Society*, 19: 393-416.

Samson, M., Babson, O., MacQueen, S. et al. 2000. *The macro-economic implications of poverty-reducing income transfers*. Interim report to the Inter-ministerial Commission on Comprehensive Social Security. Johannesburg.

Sanders, D., Todd, C., & Chopra, M. 2005. Confronting Africa's health crisis: more of the same will not be enough. *British Medical Journal*. 331: 755-758.

Sapa. 2002. Nursery Schools that refused HIV child in court today. *Cape Times*, 13 June. [Online]. Available http://www.uct.ac.za/depts.cssr/seminars9. [2004, January 28]

Sapa. 2005. *Public hearings on the provincial budgets and expenditure review* 2001/02-2007/08. Presentation, Department of Social Development, Cape Town.

Sarason, B.R., Sarason, I.G., & Gurung, R.A.R. 1997. Close personal relationships and health outcomes: a key to the role of social support. *Handbook of personal relationships: Theory, research, and interventions*, 2ed. New York: John Wiley.

Sauerborn, R., Adams, A., & Hien, M. et al. 1996. Household strategies to cope with the economic costs of illness. *Social Science & Medicine*, 43(3): 291-301.

Save the Children. 2005. *Bottlenecks and drip feeds: Channeling resources to communities responding to orphans and vulnerable children in Southern Africa*. London Save the Children UK.

Schatz, E. 2007. Taking care of my own blood. Older women's relationships to their households in rural South Africa, *Scandanavian Journal of Public Health*. 33(69): 147-154.

Schatz, E., & Ogunmefun, C. 2005. *Caring and contributing: The role of older women in multigenerational households in the HIV/AIDS era*. Colorado: Institute of Behavioral Science, University of Colorado.

Schable, B., Chu, S.Y., & Diaz, T. 1996. Characteristics of women 50 years of age or older with heterosexually acquired AIDS. *American Journal of Public Health*. 86: 1616-1618.

Scheurich, J.J. 1994. Social relativism: A postmodernist epistemology for educational administration. In *Postmodern school leadership: Meeting the crisis in educational administration*. Maxcy, S.J, Ed. Westport: Praeger. 17-46.

Schoepf, B.G. 1988. Women, AIDS and economic crisis in Central Africa. *Canadian Journal of African Studies*. 22(3): 628-639.

Schoepf, B. 1991. Ethical, methodological and political issues of AIDS research in Central Africa. *Social Science & Medicine*. 33(7): 749-763.

Schultz, R., & Beach, S.R. 1999. Caregiver as a risk factor for mortality. The CaregiverHealth Effects Study. *Journal of African Medical Association*. 282: 2215-2219.

Schurink, E.M. 1998. Deciding to use a qualitative research approach. In *Research at grassroots. A primer for the caring professions*. de Vos, A.S, Ed.: Pretoria: van Schaik, 239-251.

Schuurmans-Stekhoven, P.M. 1992. A profile of the elderly admitted to the emergency 3 unit of Groote Schuur Hospital*:* With particular reference to their health care needs. PhD thesis. Cape Town: Department of Medicine, University of Cape Town.

Schwarz, A. n.d. Old age security. In *Age and security. How social pension can deliver effective aid to poor older people and their families*. World Bank.

Seeley, J., Kajura, C., Bachengana, M. et al. 1993. The extended family and support for people with AIDS in rural population in South West Uganda: a safety net with holes? *AIDS Care*. 5(1): 117-122.

Senegal (Republic). 2001. Senegal human rights report. Available: www.ncbay.com/refernce/country/humanrights_toc.html?code=sg [2008, February 4].

Shaik, B.T., & Hatcher, J. 2004. Health seeking behavior and health service utilization in Pakistan: challenging the policy makers. *Journal of Public Health*. 27(1): 49-54.

Shisana, O., & Davids, A. 2004. Gender and HIV/AIDS: Focus on Southern Africa. Unpublished. Pretoria: Human Sciences Research Council.

Shisana, O., Hall, E., & Maluleke, K.R. et al. 2003. *The impact of HIV/AIDS on the health sector. National Survey of Health Personnel, Ambulatory and Hospitalized Patients and Health Facilities.* Pretoria: National Department of Health.

Shisana, O., Peltzer, K., & Zungu-Dirwayi, N. et al. 2004. *The health of our educators. A focus on HIV/AIDS in South African public schools,* 2004/5 survey. Pretoria: Human Sciences Research Council.

Shisana, O., Rehle, T., & Simbayi, L. et al. 2005. *South African National HIV prevalence, HIV incidence, behavior and communication survey*. Cape Town: HSRC.

Shisana, O., Rehle, T., & Simbayi, L. et al. 2006**.** People aged 50 years and older: the neglected group in HIV surveillance and HIV prevention: Paper read in the 16th International AIDS Conference, Montreal.

Shisana, O., & Simbayi, L.C. 2002. *Nelson Mandela/HSRC Study of HIV/AIDS: South African national HIV prevalence, behavioral risk and mass media: household survey.* Cape Town: Human Sciences Research Council.

Shore, R.J., & Hayslip, B. 1994. Custodial grandparenting: Implications for children's development. In *Redefining families: Implications for children's development*. Gottfried, A., & A. Gottfried, Eds. New York: Plenum Press. 171-217.

Sidorenko, A. 2004. Implementation of the Madrid International Plan of Action on Ageing: Research dimension. *Geriatrics and Gerontology International*. 4: 87-89

Sieber, S.D. 1973. The integration of field work and survey methods. *American Journal of Sociology*, 78: 1335-359.

Siegel, K., & Gibson, M.A. 1988. Barriers to modification of sexual behaviour among heterosexuals at risk for acquired immunodeficiency syndrome. *New York State Journal of Medicine,* 2: 66-70.

Siegel, K., Bradley, C.J., & Lekas, H.L. 2004. Causal attributions for fatigue among late middle-aged and older adults with HIV infection. *Journal of Pain and Symptom Management.* 28(3): 211-224.

Silverman, D. 1993. *Interpreting qualitative data*. London: Sage.

Simbayi, L.C., Kleintjies, S., & Ngomane, T. et al. 2006. *Psychosocial issues affecting orphaned and vulnerable children in two South African communities*. Cape Town: Human Sciences Research Council.

Skeldon, R. 1999. *Ageing of rural populations in South-East and East Asia*. Rome: Sustainable Development Department, FOA.

Skweyiya, Z. 2007. Social Development Department Budget Vote. Budget vote speech to the National Council of Provinces in Cape Town. Available: http//www.polity.org.za/article.php?a_id [2007, December 26].

Smart, R. 1999. *AIDS brief for professionals: health care workers*. Durban: Health Economics and HIV/AIDS Research Division (HEARD). University of KwaZulu- Natal.

Smart, R. 2000. *Children living with HIV/AIDS in South Africa*: *A rapid appraisal*. Pretoria: National AIDS Care and Support Task Team **(**NACCT).

Smith, S. 2001. ILO's response to HIV/AIDS in the world of work. *Sexual Health Exchange*. 4: 3-4.

Smith, D. 2002. Hospital stands firm on sacked Von Mollendorf. *Saturday Star*, Available: http://www.iol.co.za [2007 December 18].

SPSS Incorporated. 2006. *Statistical package for the social sciences* (Version 15.0). Chicago, IL: SPSS Incorporated.

Sogaula**,** N., Van Niekerk, R., & Noble, M. et al. 2002. *Social security transfers, poverty and chronic illness in the Eastern Cape: An investigation of the relationship between social security grants the alienation of rural poverty and chronic illness* (*including those associated with HIV/AIDS*). *A case study of Mount Frere in the Eastern Cape*. Cape Town: Duke University Press.

South African (Consulate). n.d. Moving South Africa Strategy. Department of Transport report. Available: www.southafrica-newyork.net/consulate/transport.htm). [2008, May 12].

South African participatory poverty assessment (SA-PPA). 1997. The experience and Perceptions of poverty: Durban: Praxis.

South African Medical Research Council (MRC). 2006. 336, 000 South Africans died from AIDS in one year. Parliament, August, Sapa.

South Africa (Republic), Department of Education. *Adult Basic Education and Training* Act. (Act 52 of 2000). Pretoria.

South Africa (Republic), Department of Health. 2002. Free State provincial home based care policy. Bloemfontein: DoH.

South Africa (Republic), Department of Health report. 2002. Reflection on a decade of Health report. Available: http://www.health-e.org.za/news/article.php? [2007, December 17].

South Africa (Republic), Department of Health. 2003. Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa. Pretoria: DoH.

South Africa (Republic), Department of Health. 2000-2005. *HIV/AIDS/TB Strategic Plan for South Africa*. Pretoria: DoH.

South Africa (Republic), Department of Health. 2007-2011. *HIV /AIDS and STI: National Strategic Plan*. Pretoria: DoH.

South Africa (Republic), Department of Social Development. 2002. National Report on the Status of Older Persons. 2002. Report to the Second World Assembly on Ageing, Madrid, Spain. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. n.d. South African policy for older persons. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. *Strategic Plan, 2006/7-2009/10 for South Africa*. Pretoria: DoSD.

South Africa (Republic), Department of Social Development. 1994-2002. *National report on the status of older persons. Report to the second World Assembly on Ageing*. Madrid, Spain: Pretoria.

South Africa (Republic), Department of housing. n.d. A new housing policy and strategy for South Africa. White paper. Pretoria: Department of Housing.

South Africa (Republic). 1996. *Constitution of the Republic of South Africa* (Act 108 of 1996). Available: http://www.info.gov.za/documents/constitution/index.htm [2007, December 28].

South Africa (Republic). 2003. *National Health Act* (Act 61 of 2003). Available: http://www.info.gov.za/gazette/acts/2003/a61-03.pdf [2007, December 28].

South Africa HIV/AIDS Operational Plan. 2003. *An operational plan for comprehensive HIV and AIDS care, management and treatment.* Pretoria: Department of Health.

South Africa (Union). 1939. Verbatim report of the proceedings of the Native Representative Council (NRC) (mimeographed, 1940). 495-497.

South African Institute of Race Relations. 1999. *South Africa survey*. Millennium edition. Johannesburg: SAIRR.

Standing, H., & Kisekka, M. 1989. *Sexual behaviour in Sub-Saharan Africa – a review and annotated bibliography*. London: Overseas Development Administration.

Statistics South Africa (StatsSA). 2006. General household survey. Pretoria. Available: www.sair.org.za/research-and-publications/th... [2009, October 29].

Statistics South Africa (StatsSA). 2007. Community Survey: Basic results. Pretoria. Available: www.statssa.gov.za/publications/CS2007Basic/CS2007Basic.pdf [2009, September 13].

Statistics South African (Stats SA). 2008. Mid-year population estimates. Available: www.statssa.gov.za [2008, October 15].

Southern African Network of AIDS Service Organizations (SANASO). 2001. Focus on Swaziland. SANASO *Newsletter*. 38: 3-6.

Spotnitz, R. 1997. Planning for the future-continued care of the adult dependent child after the elderly parent-caregiver's death: An exploratory study of the process by which aging parents prepare for the transition of care. PhD thesis. Long Beach, CA: Department of Social Work, University of California.

Stakes, R.E. 1981. Case study methodology: An epistemological advocacy. In *Case study methodology in education evaluation.* Welch, W.W., Ed. Minneapolis: University of Minnesota, Research and Evaluation Center. 31-40.

Stakes, R.E. 1995. *The art of case study research*. Thousand Oaks, CA: Sage.

Statistics South Africa. 2001. *Achieving a better life for all. Progress between Census* '96 *and 2001* Report. Pretoria: Stats SA.

Steinberg, M., Johnson, S., Schierhout, M. et al. 2002. *Hitting home: how households cope with the impact of the HIV/AIDS epidemic*. Cape Town: Henry J. Keiser Foundation and Health Systems Trust.

Stephenson, R., & Hennink, M. (2004). Barriers to family planning service use among urban poor Pakistan. *Asia Pacific Popuationl Journal.* 19: 5-26.

Stewart, D., & Shamdasani, P. 1990. Focus groups: theory and practice. *Applied Social Science Research Methods Series*, 20. Newbury Park: Sage.

Stloukal, L. 2001. Rural population ageing in poorer countries: Possible implications for rural development. *Journal of the International Institute on Ageing*. 11(4): 16-23.

Stover, J., Walker, N., & Garnett, G.P. 2002. Can we reverse the HIV/AIDS pandemic with an expanded response? *Lancet.* 360: 73-77.

Strauss, A. 1987. *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.

Strauss, A. & Corbin, J. 1998. *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2ed.). London: Sage.

Strydom, H. 2000. The knowledge base of high school pupils in the North West province on HIV/AIDS in Southern Africa. *American Journal of Public Health*, 90(7): 1042-1048.

Sundar, T.R.S., & Varghese, T. 2003. *Study report on older people and child care*.Tamil Naidu, India: International HIV/AIDS Alliance.

Swan, N. 2001. *AIDS in South Africa: Health minutes*. Available: http://www.abc.net.au/health/minutes/stories [2007, November 20].

Swart, D., Joubert, J.D., & Reddy, P. 1998. *Knowledge, perceptions and needs of older persons with reference to 1999, the International Year of Older Persons*: A qualitative study in the Western Cape. Unpublished. Parow Valley: SA Medical Research Council.

Swaziland National Strategic Plan for HIV/AIDS. 2000-2005. Prepared by the HIV/AIDS Crisis Management and Technical Committee. September 2000.

Swaziland Demographic and Health Survey (SDH) CSO. 2008**.** The 2nd National Multisectoral HIV/AIDS Strategic Plan 2006 – 2008. Available: http://www.popline.org/docs/1798/327506.html [11, June 2008].

Szirony, T.A 1999. Infection with HIV in the elderly population. Toledo: Medical College of Ohio, School of Nursing,

Takumura, J., & Williams, B. n.d. *Informal caregiving. Compassion in action: An introductory message*. Available: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2003-respite-releve/2003-respite-releve_e.pdf [2007, February 3].

Tashakori, A., & Teddlie, C. 1998. *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Thibaut, J.W., & Kelly, H.H. 1959. *The Social Psychology of groups*. New York: John Wiley.

Tawfik, L., & Kinoti, S. 2001. *The impact of HIV/AIDS on the health sector sub-Saharan Africa: the issue of human resources*. Pretoria: Support for Analysis and Research in Africa Project USAID, Bureau for Africa, Office for Sustainable Development.

Taylor, L., Seeley, & Kajura, E. 1996. Informal care for illness in rural southwest Uganda: the central role that women play. *Health Transition Review*. 6(1): 49-56.

Tewodros, A. 2004. Forgotten families: Support older carers of orphans and vulnerable children. Presentation in the Orphans and Vulnerable Children. (OVC-TG) workshop, Washington D.C.: The World Bank, March 18.

Tewodros, A., & Nhongo, T.M. 2006. Innovative programmes that address the impact of HIV/AIDS on older people in sub-Saharan Africa. *Global Ageing: Issues and Action*. 33-44.

Therkildsen, O., & Semboja, J.A. 1995. New look at service provision in East Africa. Semboja, J., & O. Therkildse, Eds. In *Service provision under stress in East Africa*: *The state, NGOs & people's organisations in Kenya, Tanzania and Uganda*. Copenhagen: Centre for Development Research. 1-34.

Thomas, A. 1998. Challenging cases. In *Investigative skills for policy and development: Finding out fast*. Thomas, A., J. Chataway, & M. Wuyts, Eds. London: Sage.

Thomson, R., & Scott, S. 1990. *Researching sexuality in the light of AIDS*: *historical and methodological issues*. Women, Risk & AIDS Project, Paper 5. London: Tufnell Press.

Timaeus, M.I., & Jasseh, M. 2004. Adult mortality in sub-Saharan Africa: evidence from Demographic and Health Surveys. *Demography*, 41(4): 757-772.

Tlou, S. 1996. Empowering older women in AIDS prevention: The case of Botswana. *Southern African Journal of Gerontology*. 5(2): 1-36.

Toms, I. 1990. AIDS in South Africa: potential decimation on the eve of liberation. *Progress Reports on Health & Development in Southern Africa*. 13-16.

Tribe, M.A. 1976. *Social security in Africa: Trends, problems and prospects. African Affairs.* 75: 410-411.

Troisi, J. 2004. *Ageing in Africa: Older persons as a resource.* Paper presented in the African Conference on Ageing, Johannesburg, August, 18-20.

Udjo, E. O. 2006. Demographic impact of HIV/AIDS on the young and elderly populations in South Africa. *Journal of Intergenerational Relationships.* 4: 23-41.

Udjo, E. n.d. *Additional evidence regarding fertility and mortality trends in South Africa and implication for population projections*. Pretoria: Statistics South Africa.

Uganda (Republic), Ministry of Health. Policies and programmes. Available: http://www.health.go.ug. [2007, December 26].

Uganda Commission on Human and Peoples' Rights. 2006. Report to the Commission on human and people's rights, presented in the 39th ordinary session of the Commission on Human and Peoples' Rights Banjul, Gambia.

Uma, N. 1997. *Dislocating cultures, identities, traditions and third world feminism*. New York: Routledge.

UNICEF. 2004. A joint report of new orphan estimates and a framework for action. New York: UNICEF.

UNAIDS. 1997. *Community mobilization and AIDS*. UNAIDS Technical update report. UNAIDS Best practice collection. Geneva: UNAIDS.

UNAIDS. 1998a. *HIV/AIDS and the workplace: Forging innovative business responses.* UNAIDS Technical Update. Best Practice Collection. Geneva: UNAIDS

UNAIDS. 1998b. *HIV-related opportunistic diseases*. Technical Update. Geneva: UNAIDS

UNAIDS. 1999. *Handbook for legislators on HIV/AIDS, law and human rights: Action to combat HIV/AIDS in view of its devastating human, economic and social impact.* Geneva: UNAIDS.

UNAIDS. 2000a. *HIV and AIDS related stigmatization, discrimination and denial: Forms, contexts and determinants. Research studies from Uganda and India. Key materials*. Geneva: UNAIDS.

UNAIDS. 2000b. *Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa.* UNAIDS Best Practice collection. Available: www.whglibdoc.who.int/unaids/2000/UNAIDS_00.29E.pdf [2008, December 11].

UNAIDS. 2000c. *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

UNAIDS. 2000d. Best practice digest. In *Current issues in HIV counseling and testing in South and Southeast Asia*. A report of a workshop held in Mumbai, India, February 1999.

UNAIDS. 2001. *Advocacy for action on stigma and HIV/AIDS in Africa*. Regional Consultation Meeting on Stigma and HIV/AIDS in Africa. Dar-Es-Salaam, Tanzania, June 4-6.

UNAIDS. 2002. *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

UNAIDS. 2003. *AIDS Epidemic Updates*. Geneva: UNAIDS.

UNAIDS. 2004a. *Report on the global AIDS epidemic*: *Fourth Global Report.* Geneva. UNAIDS.

UNAIDS. 2004b. *Coverage of selected services for HIV/AIDS prevention and care in low and middle-income countries in* 2003. Policy project. Global AIDS report. Geneva: UNAIDS.

UNAIDS. 2006. *Report on the global AIDS epidemic. Executive summary.* A UNAIDS 10th anniversary special edition. Geneva: UNAIDS.

UNAIDS. 2007. *AIDS epidemic update*: *December 2007-2008*. Geneva: UNAIDS and WHO.

UNAIDS. 2008. Report on the global AIDS epidemic. Available: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp [2008, December 25].

UNAIDS/UNICEF/USAID. 2002. *A joint report on orphans, estimates and program strategies*. Geneva: UNAIDS.

UNAIDS /WHO. 2001. *AIDS epidemic update*. Geneva: UNAIDS & WHO.

UNAIDS/WHO. 2005. *"3 by 5" Progress Report, December 2004*. Available: http://www.who.int/3by5/progressreport05/en/ [2007, August 20].

United Nations. 1948. *Universal Declaration of Human Rights*. Available: http://www.un.org/Overview/rights.html [2006, June 30].

United Nations. 1991. *United Nations Principles for Older Persons*. Principles adopted by the General Assembly for Older Persons. Resolution 46/91. New York: UN. Available: www.un.org/esa/socdev/ageing/ageipaa.htm [2007, May 10].

United Nations. 1993. *Vienna Declaration and Programme of Action*. World Conference on Human Rights. Resolution A/CONF.157/23. Available: http://www.unhchr.ch/huridocda/huridoca.nsf/(Symbol)/A.CONF.157.23.En [2007, October 30].

United Nations. 1998. *HIV/AIDS and human rights: International guidelines*. Second International Consultation on HIV/AIDS and Human Rights. Geneva, September, 24.

United Nations. 1999. *Human rights and older persons*. Compendium of extracts from the General Comment No. 6, adopted by the Committee on Economic, Social and Cultural Rights in 1995. Geneva.

United Nations. 2000. *Millennium Declaration*. Resolution adopted by the General Assembly. New York: UN.

United Nations. 2001a. *Declaration of Commitment on HIV/AIDS*. General Assembly Special Session (UNGASS) on HIV and AIDS. A/Res/S-26/2. New York: UNGASS.

United Nations. 2001b. *World population prospects. The 2000 revision: Highlights*. New York: Population Division, Department of Economic and Social Affairs.

United Nations. 2002a. *Millennium Development Goals*. Available: www.un.org/milliniumgoals/ [2005, August 23].

United Nations. 2002b. *Madrid International Plan of Action on Ageing*. New York: UN. Available: www.un.org/esa/socdev/ageing/waa/a-conf-197-9b.htm. [2006, November 30].

United Nations. 2004a. *Facing the future together*. Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa. Geneva: UNAIDS.

United Nations. 2004b. *Policy framework on HIV/AIDS*. New York: UN.

United Nations. 2004c. *Follow up to the International Year of Older Persons: Second World Assembly on Ageing*. Report of the Secretary General (A/59/164). New York: UN.

United Nations. 2005. *2005 World Summit outcome*. Resolution adopted by the General Assembly. New York: UN. (A/RES/60/1).

United Nations. 2006. *The Millennium Development Goals Report*. New York: UN. Available: www.un.org/milleniumgoals/ [2006, November 23].

United Nations. 2007a. *World population ageing*. New York: UN Economic and Social Affairs, Population Division.

United Nations. 2007b. *World population monitoring, focusing on the changing age structures of populations and their implications for development*. Report of the Secretary- General. New York: UN.

United Nations/ Help the Aged(UN/HtA). 2005. *Valletta Declaration*. Commonwealth Heads of Government meeting, Expert workshop on HIV and AIDS and Older People. Valletta, Malta.

United Nations International Children's Fund and World Health Organization. 1978. Primary Health Care. Report of the International Conference on Primary Health Care. Geneva.: World Health Organization.

United Nations Population Development (UNDP). 1991. Human Development Report, 35-36. New York: UNDP.

United Nations Population Development (UNDP). 1998. *Human Development Report in Lesotho*. Maseru: UNDP.

United Nations Population Development (UNDP). 2001. *HIV/AIDS: Implications for poverty reduction*. New York: UNDP.

United Nations Development Programme (UNDP). 2003. *Disease, HIV/AIDS and capacity implication*: a case of the public education sector in Zambia. Research Paper 2. New York: UNDP.

United Nations Population Development (UNDP). 2006. *Botswana Human Development Index*. UNDP, Human Development Report.

United Nations Development Programme (UNDP). 2007. *Making globalization work for all*. United Nations Development Programme Annual Report. New York. Available: www.undp.org/publications/annualreport2007/IAR07-ENG.pdf [2008, November 26].

United Nations Development Programme (UNDP). 1992. *Young women: silence, susceptibility and HIV infection. Age and gender as independent variables in the acquisition of HIV*. New York: UNDP.

UNESCO. 2000. *The Dakar framework for action, education for all: meeting our collective commitments*. World Education Forum. Dakar, Senegal. April, 26-28.

UNESCO. 2002. EFA global monitoring report, 2002: is the world on track? Paris: UNESCO. Available: ww.unesco.org/education/efa/monitoring/monitoring_2002.shtml. [2007, October 22].

UNICEF. 1984. Overview of evaluation activities in UNICEF. Unpublished. New York: UNICEF.

UNICEF/UNAIDS. 1999. *Children orphaned by AIDS. Frontline responses from eastern and southern Africa*. New York: UNICEF division of communication.

UNICEF. 2001. *The state of the world's children 2001*. New York: UNICEF

UNICEF. 2003. *Africa's orphaned generations*. Annual Report. New York: UNICEF.

United Nations Population Fund **(**UNFPA). 2004. *Integrating HIV voluntary counseling and testing services into reproductive health setting. Stepwise guidelines for programme planners, managers and service providers*. New York: UNFPA.

United Nations Population Fund **(**UNFPA). 2002a. *Population ageing and development*. Operational challenges in developing countries. New York: UNFPA.

United Nations Population Fund **(**UNFPA). 2001. *Preventing infection, promoting reproductive health. UNFPA's Response to HIV/AIDS*, New York: UNFPA.

United Nations Population Fund (UNFPA). 2002b. *Situation and voices. The older poor and excluded in South Africa and India.* Technical Support Division: New York: UNFPA.

Urassa, M., Ties Boerman, J., Ng'weshemi, J. et al., 1997. Orphanhood, child fostering and the AIDS epidemic in rural Tanzania. *Health Transition Review.* 2(7): 141-153.

United Agency for International Development (USAID). 1996. *Performance monitoring and evaluation. conducting key informant interviews.* Center for Development Information and Evaluation. TIPS, 2. Arlington: USAID.

United Agency for International Development (USAID). 2002. *HIV/AIDS prevention, care and support across faith-based communities: An annotated bibliography of resources*. HRN-A-00-97-0017-00. Arlington, VA: USAID.

United States Census Bureau (USCB). 1998. *Focusing on HIV/AIDS in the developing world. World population profile*. Report WP/98. Washington, DC: USCB

United States Census Bureau (USCB). 2005. *International database*. Washington D.C.: USCB.

United States Presidential Emergency Plan for AIDS Relief (PEPFAR). 2008. *Pepfar operational plan*, June 2008. Available: http://www.pepfar.gov/documents/organization/107838 [2008, November 22].

Uys, L. 2003. Longer-term aid to combat AIDS. Editorial. *Journal of Advanced Nursing*. 44(1): 1-2.

Valdes, B., & Henriques, J. 1983. Health status of the Cuban people. *International Journal of Health Services.* 13: 479-86.

Valenti, W.M. 1995. Infection control, human immunodeficiency virus, and home health care: Risk to the caregiver. *American Journal of Infection Control.* 23(2): 78-81.

Valsiner, J. 1986. *The individual subject and scientific psychology*. New York: Plenum.

Van der Geest, S. 1997. Between respect and reciprocity: managing old age in rural Ghana. *Southern African Journal of Gerontology*. 6(2): 20-25.

Van Praag, E. n.d. Continuum of care and support: HIV/AIDS prevention. Arlington, VA: Care Department, Family Health International.

Vapi, X. 2004. Grants help destitute spring the poverty trap. Far from creating dependency, social grants raise the odds of finding work. *Cape Argus*, December 12. p 6.

Walt, G. 1994. *Health policy: An introduction to process and power. People, government and international agencies – who drives policy and how it is made*. Johannesburg: Witwatersrand University Press.

Webb, D. 1997. The sexual and economic politics of (re) integration: HIV/AIDS and the question of stability in Southern Africa. *SAfAIDS News.* 5(4): 2-6.

Weidlich, B. 2007. Gays and lesbians left out of AIDS policy. *The Namibian*, 26 March. 3.

Weiss, H.A., Quigley, M.A., & Hayes, R.J. 2000. Male circumcision and risk of HIV infection in sub-Saharan Africa: a systematic review and meta-analysis. *AIDS 2000.* 14(15): 2361-2370.

Welman, J.C., & Kruger, S.J. 2002. *Research methodology for business and administration science.* 2nd ed. Oxford: Oxford University Press.

White, H. 2002. Combining quantitative and qualitative approaches in poverty Analysis. *World Development.* 30(3): 511-522.

Whiteside, A., & Suntner, C. 2000. AIDS: *The challenge for South Africa*. Cape Town: Human & Rousseau, and Tafelberg.

Williams, A. 2003. *Ageing and poverty in Africa: Ugandan livelihoods in a time of HIV/AIDS*. Hampshire: Ashgate.

William, G., & Tamale, N. 1991. *The caring community: Coping with AIDS in urban Uganda.* Action Aid, London African Medical & Research Foundation. Nairobi: AMREF.

Wilson, D. 2000. *Issues in home care in Southern Africa*, presentation to Regional Norwegian-Swedish HIV/AIDS Meeting: Strengthening integration of HIV/AIDS into Development Cooperation, 16-17 November, Zombe, Malawi.

Woelk, G., Jackson, H., Kerkhoven, R. 1997. *Do we care? The cost and quality of community home based care for HIV/AIDS patients and their communities in Zimbabwe*, Harare: University of Zimbabwe, SAfAIDS and , Ministry of Health and Child Welfare.

Wolcott, H.T. 1994. *Transforming quantitative data: Description, analysis, and interpretation.* Thousand Oaks, CA: Sage.

Wooten-Bielski, K. 1999. HIV and AIDS in older adults. *Geriatric Nursing.* 20(5): 268-272.

World Bank. 1993. *Uganda: Growing out of poverty – a World Bank country study,* International Bank for reconstruction and development (IBRD), Washington D.C.

World Bank. 2006. *Grandmothers promote maternal and child health*: *the role of* i*ndigenous knowledge systems managers*. Available: www.worldbank.org/afr/ik/iknt89.ht [2006, June 23].

World Health Organization. 1978. *Primary Health Care, Report of the International Conference on Primary Care*, Alma Ata. Geneva: WHO.

World Health Organization. 1996. *Integration of health care delivery. Report of WHO study group*. WHO Technical Report Series No. 861. Geneva: WHO.

World Health Organization. 2000. *Active ageing: A policy framework*. Geneva: WHO.

World Health Organization. 2001. *Information needs for research, policy and action on ageing and older persons, definition of an older or elderly person.* WHO Statistical Information system. Available: http://www3.who.int/whosis/mds/mds_definition [2005, October 23].

World Health Organization. 2002a. *The impact of AIDS on older people in Africa*: *Zimbabwe case study*. Geneva: WHO.

World Health Organization. 2002b. *Guidelines on Care and Support in Resource Limited Settings.* Geneva: WHO.

World Health Organization. 2002c. *Policy Framework for Community Home Based Care in Resource Limited Settings*. Geneva: WHO

World Health Organization. 2003. Report on the review of Primary Health Care in the African region. Brazzabille: WHO, Regional Office for Africa.

World Health Organization. 2004a. *Active ageing:* Towards age-friendly Primary Health Care. *Active Ageing Series*. Geneva: WHO.

World Health Organization. 2004b. *Changing history*. World Health Report. Geneva: WHO.

World Health Organization. 2004c. *Health sector reform and district health systems. District management team training module*. Brazzaville: WHO Regional Office for Africa.

World Health Organization. 2005. *Health action in crisis, Lesotho*. Geneva: WHO.

World Health Organization. 2006. *Taking stock: Health worker shortages and the response to AIDS*. World Health Report. Geneva: WHO.

World Health Organization. n.d. *STDs case management: A guide to syndromic management.* Geneva: WHO.

WHO/UNICEF/Government of Mali. 1999. Report on the review of the implementation of the Bamako Initiative in Africa. Bamako, Mali, March 8-12.

Yamagishi, T. 1987. An exchange theoretical approach to network positions. *In Social exchange theory*. Cook, K.S. Ed. London: Sage.

Yin, R.K. 1989. *Case study research: Design and methods*. Newbury Park, CA: Sage.

Yin, R.K. 1994. *Case study research: Design and methods*. 2nd ed. Applied Social Research Methods Series. Vol 5. Thousand Oaks, CA: Sage.

Zejly, A., & Galibaka, G. 2005-2009. *Country strategic paper. Republic of Senegal*, 2005-2009 *report*. Senegal.

Zelenetz, P.D., & Epstein, M.E. 1998. *HIV in the elderly - AIDS Patient Care STDS*. New York: Department of Medicine, North Shore University Hospital.

Zierler, S., Cunningham, W.E, & Andersen, R. et al. 2000. Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *Journal of Public Health*. 90(2): 208-215.

Zwarenstein, M., & Barron, P. 1992. *Managing Primary Health Care in South Africa at the district level.* The Medical Research Council/Institute for Urban Primary Health Care Workshop. Health Systems Division of the Centre for Epidemiological Research in South Africa. Parow Valley: SA Medical Research Council.

ABSTRACT

Background and objectives: Never in the modern history of public health has there been as widespread and devastating a disease that has threatened human progress at all levels – human rights, human development and achievements in Public Health – as HIV and AIDS. Sub-Saharan Africa bears the heaviest burden of the pandemic globally. Of the 33 million people globally estimated to be living with HIV and AIDS at the end of 2007, 67 per cent lived in the sub-region, which accounted for 72 per cent of AIDS deaths worldwide. South Africa, second only to Swaziland, carries the heaviest burden of the epidemics. Much of the burden of care for persons living with HIV and AIDS (PLWHA) and orphaned and vulnerable children (OVC) falls on older persons, who are largely unsupported. The main aim of this dissertation and study was to examine the situations and support needs of older persons who care for PLWHA and OVC in three South African provinces, and based on this evidence, to develop a policy framework, to be used as a tool by the government and other stakeholders to guide the formulation of policy to support older carers at the district level.

Method: Reviews were carried out of the relevant literature and of policies on HIV and AIDS and older persons. A mixed-methods approach, in which quantitative and qualitative methods are used in combination, was employed to conduct an empirical study to learn of older carers' situations and support needs. A multi-level sampling technique was used to recruit a sample of 305 persons aged 50 years and over who render care to PLWHA and/or OVC in their household, for a survey conducted in urban settings and non-urban settings in the three provinces. The respondents were identified from lists of non-profit organisations (NPOs) that service households affected by HIV and AIDS in which an older carer resides. A structured questionnaire with fixed-response and open-ended items was used to gather data in the following domains: i) socio-demographic information; ii) household information; iii) the respondents' health and well-being; iv) their knowledge about HIV and AIDS; v) caregiving activities to PLWHA; vi) caregiving activities to OVC; and vii) support from the government/district and other agencies. Trained fieldworkers administered the questionnaires in the respondents' homes. Ten of the 305 survey respondents were purposively selected for follow-up, qualitative in-depth interviews by the researcher, using a semi-structured interview schedule, and the data were written up as case studies. Five representatives of relevant government departments and three representatives of NPOs that serve older carers, across the

three provinces were interviewed as well by the researcher, as key informants on policies and programmes that may provide for older carers. The survey data were captured using SPSS 15.1 and analysed descriptively. The qualitative data were transcribed, translated from Xhosa into English, and the transcripts coded and content analysed. Results of the analyses of the three data sets were later triangulated.

Results: An analysis of the survey data showed that the majority of the older carers were widowed, lacked formal education, were poor, and relied on a social old age grant for income. Moreover, they were found to carry a triple burden of care. They not only rendered care to PLWHA and OVC, but had to cope with their own faltering health, exacerbated by the stress of caregiving and related challenges. In the majority of cases, the PLWHA for whom they cared was their adult child. The caregiving was rendered under conditions of severe deprivation, a lack of formal support and limited support from NPOs. Most carers were knowledgeable about HIV and AIDS, but some held fatalistic beliefs about the disease being a punishment from God. Most lacked basic equipment for universal protection against HIV infection, such as latex gloves and plastic aprons, and most lacked piped water and sanitation facilities inside their dwelling. The majority lived in multi-generational households in which two grandchildren on average resided. The case study data highlighted the levels of stress that the carers experienced, which they perceived aggravated chronic conditions such as hypertension and diabetes, and created psychological conditions such as insomnia, a lack of concentration and bouts of crying. Virtually none of these carers had disclosed the status of the PLWHA to their neighbours for fear of stigmatisation and discrimination. Some spent a great deal of their meagre income on so called traditional healers in desperation to find a cure for the PLWHA. Most feared what would become of their grandchildren should the carer die. All endeavoured to ensure their grandchildren were schooled. Information gathered from the key informants when analysed confirmed that the government has no policy on HIV and AIDS that targets, or is inclusive of, older persons and their needs. The government informants were largely ignorant of the plight of older carers, but were open to putting older carers' issues on policy agendas. NPO informants complained about a lack of consultation by the government, and the non-involvement of older persons or their representative organisations in policy formulation processes. They identified bureaucracy and the slow pace at which the government works as a major barrier to older persons' participation in these processes.

A major objective of the dissertation was to develop a Policy Framework for collective action by stakeholders. The framework is the first of its kind in the sub-Saharan Africa sub-region to address issues relating to the impact of HIV and AIDS on older persons, and is intended to guide all relevant stakeholders in policy formation and service delivery to benefit older carers. The framework is divided in four sections: 1) desired outcomes – the results if the policy recommendations are realised; 2) bases for action – empirical evidence that exists on a need to support older carers; 3) policy recommendations – steps proposed for implementation by stakeholders to realise the desired outcomes; and 4) potential indicators – measurements for stakeholders to gauge the extent to which the recommendations have been successfully implemented by the role players.

Conclusions: The study showed that older carers are not supported by the South African government in ways that could meet their multifaceted and complex needs, and are supported only to a limited extent by NPO, in a context of scarce resources and other priorities. Older carers in urban areas are faced with similarly deprived socio-economic circumstances as those of their rural counterparts, but the urban carers have more opportunities to acquire income generation skills to support themselves and their dependents, and to access assistive resources. The study highlightes a need for a national policy on older persons and HIV and AIDS; in particular, the need for a programme to deal with stigma and the isolation of older carers in the community.

Key words: Older persons; caregiving; HIV and AIDS; orphans and vulnerable children; support needs; stigma; policy framework; non-profit organisations; district; government.

ANNEXURE 3

THE RESPONDENTS' RESOURCE PAMPHLET*

To be used to access support needed

NAME OF PROVINCE: Western Cape **Location type : Urban**

Organisation name	Address	Phone No.	Contact person	Resource offered
Philani Nutrition Center	Khayelitsha Site C Phaphani St 7784	(021)387 5124	Dr I. Le Roux	**Child Nutrition Advice and Support and health provision**
J.J Zwane Centre	NY7 Gugulethu Nyanga	021- 633 5033	Rev. Xhapile	**Referrals/food parcels/training**
Ilitha Labantu	22 Gugulethu Nyanga	021-633 2383	Ms M. Monakali	**HIV/AIDS Counselling and advice**
Beautiful Gate	Nyanga/Crossroads Nyanga	(021) 371 7107	Sr Frances	**HIV/AIDS advice, social work/counseling and support/ accommodation**
Missionaries of Charity (Mother Theresa's Nuns)	Khayelitsha Section E 7784	(021)361 3365	Sister Lwanga	**Food Distribution, HIV/AIDS education and accommodation**
MSF: Medicne Sans Frontieres	Khayelitsha Site B Sulani Drive 7784	(021)364 5490	Mr E. Goemaere	**Antiretroviral drug treatment, counseling and information**
GAPA Grandmothers Against Poverty and AIDS	Khayelitsha Section E Griffiths Mxenge 7784	(021)686 6369	Ms K. Brodrick	**General Support to Grandmothers PLWHAs**
NOAH Neighborhood Old Age Homes	Khayelitsha	(021)	Ms N. Mangcu	**HIV/AIDS Training and counseling to PLWHA and OVC caregivers**
Community Health Center Khayelitsha	Khayelitsha 7784	(021)360 3480	Sr L. Matinise	**Medical consultation, counseling, information and support**
SHAWCO	Nyanga Sithandathu Ave 7750	(021) 386 1603	Ms K. Ngozo	**Training, Food distribution, and counseling**
Treatment Action Campaign (TAC)	Khayelitsha Site B 7784	(021)364 5489	Ms T. Thembeka	**HIV/AIDS advocacy, legal advice and counseling**
Red Cross Society	Khayelitsha Site C 7784	(021)363 0016	Sr C. Nomala	**Training, food distribution, home based care, non statutory social work, advocacy and counseling**
Provincial Administration of the Western Cape (PAWC)	Khayelitsha Lingelethu Bld Bhonga Drive 7788	(021)361 4970	Ms P. Bhaca	**Social Work\Welfare services, referrals and counseling**

*Pamphlet for the Western Cape sub-sample. Similar pamphlets with information relevant to that setting were handed to respondents in the other two provinces, specific to the urban or non-urban setting.

ANNEXURE 2

THE SURVEY QUESTIONNAIRE

Data Collection Form No: | | | |

SECTION 0: IDENTIFICATION DATA

Interviewer's name:…… Preferred language of respondent…….

Date: (dd/mm/yy) / /

Geographical area:

Urban	Non urban	Province
1	2	

Type of dwelling :

Brick house	Mud house	Shack	Other(specify…
1	2	3	4

Residential address:

……

INTERVIEW LOG: (Refusals/no eligible respondent at home to participate)

	Visit 1	Visit 2	Visit 3
Time			
Comment			

Comment codes : Interview completed (1), Appointment made for another day (2)

Refused to participate (3), Did not complete interview (4),
Other 5 (Specify**:……**

Interviewer starting time: | | | | |

Interview stopping time: | | | | |

SECTION 1

1 Biographical Information

1.1 In what year were you born? | | | | |

1.2

Sex	Male	1
	Female	2

1.3 Language mainly spoken by the respondent: (**as identified by respondent**)

isiXhosa	isiZulu	Sotho	English	Afrikaans	Other
1	2	3	4	5	6

1.4 What is your nationality?

a. South African	1
b. Other: Specify……	2

1.5 What is your marital status?

a. Married	1
b. Widowed	2
c. Separated	3
d. Divorced	4
e. Never married	5
f. Living together	6

1.6 What is your highest education qualification? **(tick one option only)**

a. No schooling	1
b. Sub A	2
c. Sub B	3
d. Standard 1	4
e. Standard 2	5
f. Standard 3	6
g. Standard 4	7
h. Standard 5	8
i. Standard 6	9
j. Standard 7	10
k. Standard 8	11
l. Standard 9	12
m. Standard 10	13
n. Teacher Diploma	14
o. Nursing Diploma	15
p. Degree	16
q. Other: specify……	17

1.7. From which of the following sources does your household derive income? **(more than one answer possible)**

	Respondent	Household
a. Child support grant	1	2
b. Social old age Pension	1	2
c. Employer Pension	1	2
d. Foster care grant	1	2
e. Care dependency grant	1	2
f. Child disability grant	1	2
g. Unemployment insurance	1	2
h. Workmen's compensation	1	2
i. Remmittance from family member(s)	1	2
j. Employed (full-time)	1	2
k. Employed (part time/odd jobs)	1	2
l. Self employed (e.g. hawking)	1	2
m. Donation by private welfare organisation(s) (e.g. church)	1	2
n. No income	1	2

SECTION 2

HOUSEHOLD INFORMATION

I am now going to ask you about all the people who live in this household? I only need to know their first names, gender, age and relationship to you.

2.1 **Interviewer**: Complete the grid below for all persons who live in the household. Probe, to check that all co-residents have been mentioned.

Definition of "live in this household": All persons who live in the household (i) at least four months of the year, and (ii) eat from a common pot when they are here.

Person Code	First Name	Gender M = 1 ; F = 2	Age (years)	Relationship to respondent	Attends school = 1 Does not attend = 2 N/A. = 3	Working/employed (earning weekly/monthly salary) Yes = 1; No = 2; N/A = 3
1.						
2.						
3.						
4.						
5.						
6.						
7.						

Relationship to respondent Code: 1 = Head of household
2 = spouse, partner
3 = son,
4 = daughter
5 = Grandchild
6 = Mother/father in-law
7 = Son/daughter in-law
8 = Brother/sister in-law
9 = Aunt, uncle
10 = Niece, nephew
11 = Sister, brother
12 = Other relative
13 = Lodger
14 = Household helper
15 = Father, mother

2.2 Are you the head of this household?

Yes = 1	**No** = 2

2.3 How long have you lived in this township/village (years)?

a. < 1 year	1
b. 1 - 2 years	2
c. 3 - 5 years	3
d. 6 - 10 years	4
e. > 10 years	5

2.4 How long have you lived in this house?

a. < 1 year	1
b. 1- 2 years	2
c. 3- 5 years	3
d. 6- 10 years	4
e. > 10 years	5

2.5. Where does this household get water? **(more than one answer possible)**

	Yes	**No**
a. From a river/water stream/pond	1	2
b. Tap (inside house)	1	2
c. Tap (in the yard)	1	2
d. Communal tap	1	2
e. Other (Specify……		3

2.6 What type of toilet facility does this dwelling have?

a. Flush toilet inside house.	1
b. Flush toilet in yard.	2
c. Communal flush toilet	3
d. Pit latrine	4
e. Bucket toilet	5
f. Chemical toilet	6
g. No toilet – (use the bush, etc.)	7
h. Other (Specify….	8

2.7 Which forms of energy are used in this house? (**more than one answer possible**)

	Yes	No
a. Timber/wood	1	2
b. Electricity	1	2
c. Coal/anthracite	1	2
d. Paraffin	1	2
e. Gas	1	2
f. Other (Specify……		

2.8 How many rooms does this house have? **(including kitchen but excluding bathroom/toilet)**

a. One room	1
b. Two rooms	2
c. Three rooms	3
d. > Three rooms	4

2.9. I am going to read you a number of statements. Which one would you say best describes your household situation? **(Interviewer; read options to respondent)**

	Yes	No
a. Not enough money for basic things like food and clothes	1	2
b. Have enough money for food and clothes, but short on many other things	1	2
c. We have most of the important things, but few luxury goods (TV, refridgerator)	1	2
d. Some money for extra things such as going away on holidays; luxury goods	1	2
e. No response	1	2

2.10. From which of the following sources does this household derive income? **(multiple answers possible)**

	Yes	No
a. Government child support grant	1	2
b. Social old age pension	1	2
c. Employer Pension	1	2
d. Remittance from family member(s)	1	2
f. Employment (full-time)	1	2
g. Employment (part time)	1	2
h. Self employment	1	2
i. Hawking/odd jobs	1	2
j. Welfare organisation(s) (e.g. church, NGO)	1	2
k. No income	1	2
l. Other (Specify…		

2.11. If you do not derive any income from government, what is the reason(s) for this? **(do not read options)**

	Yes	No	N/A
a. Don't know where to apply	1	2	3
b. Government offices too far (in town)	1	2	3
c. Don't have legal papers (e.g. birth certificate; child clinic card, ID book)	1	2	3
d. Have applied but I am still waiting	1	2	3
e. Not eligible	1	2	3
f. Other (Specify…….			

SECTION 3

I am now going to ask you about your health and well-being

3.1 How would you rate your health at present?
(**read out the options loud)**

Excellent	Good	Fair	Poor
1	**2**	**3**	**4**

3.2. Compared to people of your age, would you say your health is "better", the "same" or "worse" than their's?

Better	Same	Worse
1	**2**	**3**

3.3 Which of the following health conditions do you have at present? Is the condition being treated at a clinic or by a doctor?

Health condition

	Yes, not being treated	**Yes, being treated**	**No, do not have**	**Not sure**
a. Stress	1	2	3	4
b. Depression	1	2	3	4
c. Hypertension (high blood pressure)	1	2	3	4
d. Arthritis or rheumatism	1	2	3	4
e. Diabetes	1	2	3	4
f. Eye sight problem	1	2	3	4
g. Hearing problem	1	2	3	4
h. Heart condition	1	2	3	4
i. Stroke	1	2	3	4
j. TB (Tuberculosis)	1	2	3	4
k. Cancer	1	2	3	4
l. Asthma	1	2	3	4
m. Epilepsy (convulsions or fits)	1	2	3	4
n. Stomach ulcer(s)	1	2	3	4
o. Loss of memory	1	2	3	4
p. Kidney problem	1	2	3	4
q. Shortness of breath	1	2	3	4

SECTION 4

HIV/AIDS KNOWLEDGE AND AWARENESS

I am now going to ask you questions about HIV/AIDS

4.1 Do you know what HIV/AIDS is?

Yes	No
1	2

(If No, go to 5.1; if yes, go to 4.2)

4.2 I am going to read you a list of statements about AIDS. Please tell me whether you Agree, Disagree or are Not sure with each statement. **(interviewer read statements and response options to respondent)**

AIDS is…	Agree	Disagree	Not sure
a. A disease caused by a germ(virus)	1	2	3
b. A disease caused by witchcraft	1	2	3
c. A disease caused by poor nutrition	1	2	3
d. Punishment from God	1	2	3
e. Other (Specify…….			

4.3 Where did you get your knowledge about HIV/AIDS ? **(multiple responses possible)**

	Yes	No
a. From television	1	2
b. From the radio	1	2
c. In newspapers	1	2
d. In pamphlets/ magazines.	1	2
e. From a doctor/nurse	1	2
f. Other (Specify…..		

4.4 Do you understand the information given about HIV/AIDS?

Yes	No	Not sure
1	2	3

4.5 In your opinion, is it possible to transmit HIV by means of the following?
(read the options aloud)

	Yes	No	Don't Know
a. Kissing	1	2	3
b. Sitting on a toilet seat	1	2	3
c. Touching someone with HIV/AIDS	1	2	3
d. Drinking from the same mug	1	2	3
e. Breathing the same air as an HIV+ person	1	2	3
f. Exchanging bodily fluids	1	2	3
g. Unprotected sex	1	2	3
h. Other(specify…….			

4.6 Can older persons be infected with HIV?

Yes	No	Not sure
1	2	3

(If No go to 5.1; If not sure, go to 5.1; if yes go to 4.7)

4.7 How can older persons protect themselves from being infected with HIV? **(Read options to the respondent)**

	Yes	No	Don't know
a. Wear protective gloves when washing a sick person with AIDS.	1	2	3
b. When doing washing, do his/her's separately	1	2	3
c. Use a condom if sexually active	1	2	3
d. Drinking traditional herbs (muti)	1	2	3

SECTION 5

CAREGIVING TO A PLWHA

You are at present caring for an adult person (someone aged between 18 and 49 years) in this household. I would like to ask you about this caring. By caregiving I mean: cooking, feeding, washing, providing medication, taking the sick person to a doctor/clinic or hospital because the person is unable to do these tasks him/herself.

5.1 The person you are caring for: does this person has AIDS?

Yes	No
1	2

(if No, go to 5.5)

5.2 Is there someone who helps you with daily caregiving to the sick person(s) with HIV/AIDS?

Yes	No
1	2

(if No, go to 5.14; if yes go to 5.3)

5.3 If Yes, who is this person(s)?

	Yes	No
a. My husband/partner	1	2
b. My other child(ren)	1	2
c. My grandchild(ren)	1	2
d. NGO/CBOs (counselors; home carers; home visitors)	1	2
e. Community nurse(s)	1	2
f. Nurse aid	1	2
g. Neighbour(s)	1	2
h. Other relative	1	2
i. Friends	1	2

j. Other (Specify…		3

5.4 What types of help or support does this/these person(s) provide?
(more than one answer accepted)

Support provided

	Yes	No
a. Financial	1	2
b. Washing the PLWHA	1	2
c. Feeding	1	2
d. Administering medication	1	2
e. Transporting the PLWHA to a health care facility	1	2
f. Emotional/spiritual	1	2
g. Other (Specify……..		3

5.5 Are there things you would like to learn to improve your caregiving activities?

Yes	No
1	2

(If No, go to 5.7; if yes go to 5.10)

5.6 If Yes, which of the following would be of help to you? **(more than one answer possible)**

	Yes	No
a. Learn more about HIV/AIDS	1	2
b. Learn how to care better for a PLWHA	1	2
c. Guidance on how to access government assistance to care for the PLWHA	1	2
d. Other (Specify……..		3

5.7 On average how often in the past year have you sought medical treatment for the PWHA in your household ? **(read options to respondent)**

a. 2-3 times a month	1
b. Once a month	2
c. Less often than once a month	3
d. Other (specify……	4

5.8 How helpful overall have you found the health providers at the clinic/hospital when you visit with the PLWHA? **(If never visited clinic/hospital with PLWHA, go to 1.36)**

a. Very helpful	1
b. Helpful	2
c. Unhelpful	3
d. Very unhelpful	4

5.9 Does anyone else in your family knows about the PWHA's condition?

Yes	No
1	2

(If No, go to 5.12; If yes go to 5.10)

5.10 If Yes, who is this?

Person(s) who knows

	Yes	No	Don't know
a. My partner/husband	1	2	3
b. My other child(ren)	1	2	3
c. My grandchild(ren)	1	2	3
d. My sister/brother	1	2	3
e. My mother/father	1	3	3
f. Other (Specify…			

5.11 How do other members of your household behave towards the PLWHA? **(answer each) ?**

	Yes	No	Can't say
a. They do not treat him/her any differently	1	2	3
b. They are understanding and supportive	1	2	3
c. They avoid all physical contact with the person	1	2	3
d. They blame the person for contracting the disease	1	2	3
e. If no, why? (explain…..	1	2	3

5.12 How many people in the neighbourhood know about the PLWHA 's condition? **(answer each)**

	Yes	No	Don't know
a. Only one person	1	2	3
b. Some people	1	2	3
c. It is common knowledge	1	2	3
d. Nobody	1	2	3

5.13 During caregiving to the PLWHA, does s/he ever **(answer each)**

	Yes everytime	Yes sometimes	No/ Never
a. Shout or get angry with you ?	1	2	3
b. Hit or throw things at you ?	1	2	3
c. Accuse you of being responsible for his/her illness ?	1	2	3
d. Refuse to talk to you ?	1	2	3
e. Refuse to take food from you ?	1	2	3

5.14 Which other person(s) in this household who are sick (but not with AIDS) do you

care for? **(Interviewer: refer to the household grid for person code) ([don't include grandchildren here)**

Person	Code
a.	
b.	
c.	
d.	
f.	

I am now going to talk to you about person(s) in this household who have died in the last two years.

5.15 To your knowledge, is there someone in your household who died from AIDS in the past two years?

Yes	No	Not Sure
1	2	3

(If No, go to 6.1 ; If Not sure, go to 6.1 ; If Yes, go to 5.16)

5.16 How was this person(s) related to you? **(multiple answers possible)**

	Yes	No
a. Adult child(ren)	1	2
b. Husband/wife	1	2
c. Grandchild	1	2
d. Other (……		

5.17 On average how many months did you care for this/these person(s) before s/he died (PLWHA) from the time s/he/ they became sick with AIDS?

a. Less than one month	1
b. 1 - 4 months	2
c. 5 - 7 months ,	3
d. 8 - 10 months	4
e. 10+ months	5
f. Unsure	6

5.18 Did the person(s) who died live in this house all his/her life?

Yes	No
1	2

(If No, go to 5.19; if yes, go to 5.20)

5.19 If No, where did s/he/they live when s/he/they became sick with AIDS?

a. In another country	1
b. In the city/an urban area	2
c. In a rural area	3
d. Don't know	99

5.20 From whom did you first learn or hear about his/her/their illness?

	Yes	No
a. From him/her/them	1	2
b. From a nurse/doctor at clinic/hospital	1	2
c. From a CHW (Community Health Worker)	1	2
d. From his/her partner	1	2
e. Other (specify….		

5.21 Did this/these person(s) who died previously contribute to the household financially?

Yes	No
1	2

SECTION 6

CARING FOR THE ORPHANS/GRANDCHILDREN

I am now going to ask you about the grandchildren you are caring for in this household (By caring I mean:cooking, feeding, washing, emotional, minding, counseling, disciplining, helping with school work, playing etc).

6.1 Are all your grandchildren in school?

Yes	No
1	2

(If No, go to 6.2; If Yes, go to 6.3)

6.2 If some are not in school, why are they not in school?
(more than one answer possible)

	Yes	No
a. There is not enough money for school	1	2
b. They (s/he) refuse to go to school	1	2
c. They (s/he) are too young to go to school	1	2
d. They (s/he) have finished school	1	2
f. They (s/he) are sick/disabled	1	2
g. They (s/he) are HIV infected	1	2
h. Other (Specify……	1	2

6.3 Who pays for their school expenses? **(more than one answer possible)**

	Yes	No
a. I pay for them	1	2
b. Other members of the family	1	2
c. Me and other member(s) of the family	1	2
c. Child support grant	1	2
d. Nobody pays for them/ they have no uniforms	1	2
e. Other (Specify…….	1	2
f. Don't know		3

6.4 Why are you caring for these child (ren)? **(do not read options)**

	Yes	No
a. I have no choice	1	2
b. Nobody else will/to care for them	1	2
c. They are part of my family	1	2
d. Other (specify…….		3

6.5 In which area(s) of caring for these children do you need support or help, and how much? **(read each option loud)**

Care domain	A lot of support/help	Some support/help	Don't need support/help
a. Financial	1	2	3
b. Physical	1	2	3
c. Emotional	1	2	3
d. Social (e.g. discipline)	1	2	3
e. Other (specify…….			

6.6 Which area(s) in which you spend money caring for the children are most costly; costly and least costly? **(interviewer must read options)**

Expense area	Most costly	Costly	Least costly
a. School fees and uniforms	1	2	3
b. Health care	1	2	3
c. Food	1	2	3
d. Clothes	1	2	3
e. Transport	1	2	3
f. Other (Specify…….			

6.7 Is there a grandchild(ren) in this household who has been diagnosed with HIV?

Yes	No	Don't know
1	2	3

(If No, go to 6.9; If Don't know, go to 6.9; If Yes, go to 6.8)

6.8 If Yes, what are the major care needs of this (these) child(ren)? **(do not read the options to** respondent)

	Yes	No
a. Access to treatment (medication) for their condition	1	2
b. Counselling/emotional support	1	2
c. Nutrition support	1	2
d. Physical care (e.g. discipline)	1	2
e. Other(Specify……	1	

SECTION 7

LOCAL/DISTRICT GOVERNMENT AND GENERALSUPPORT

Now I will ask you about the type of support you receive from government that helps you with caregiving (By support I mean: Government grants; free medicine; transport to clinic/hospital; food parcels/voucher)

6.9 Do you receive any support from government places that helps you specifically with caregiving for persons infected with or affected by AIDS?

Yes	No
1	2

(If No, go to 6.11; if yes go to 6.10)

6.10 If Yes, indicate how much you agree or disagree with the following statements **(read each statement and circle the appropriate code)**

	Agree	Disagree	Not sure
a. The support I received from government is sufficient	1	2	3
b. The support I received from government is not sufficient	1	2	3
c. The support from government meets my basic caregiving needs	1	2	3
d. Government needs to give more support to people who care for the PLWHA	1	2	3

6.11 If No, Which of the following types of support would help you to meet your caregiving needs better? **(read each option and circle the appropriate answer)**

Type of support

	Yes	No	Not Applicable
a. Nutrition (e.g.food parcels)	1	2	3
b. Financial or money vouchers	1	2	3
c. Improved housing (e.g. inside toilet; bathroom)	1	2	3

6.12 Do you agree or disagree with the following statements? **(read each statement)**

	Agree	Disagree	Don't know
a. Government is committed to support PLWHA and those affected by HIV/AIDS	1	2	3
b. Government provides sufficient money to fight HIV/AIDS	1	2	3
c. Government provides enough support to households affected by HIV/AIDS	1	2	3
d. Government provides enough support to children affected by HIV/AIDS	1	2	3

Now I want to know about other forms of support ,other than from government, that you receive

6.13 Do you belong to a faith/religious body?

Yes	No
1	2

(If No go to 6.15; if yes go to 6.14)

6.14 How often do you visit your place of worship?

a. Every Sunday or more often than that	1
b. Two/three times a month	2
c. Once a month	3
d. Less than once a month	4
e. Once a week	5
f. Twice a week	6
g. Stopped attending because of my caregiving responsibilities	7
h. Once a year (Christmas; Good Friday etc)	8

6.15 Do you belong to any of the following groups? **(read options to respondent)**

	Yes	No	Not applicable
a. Community support group (senior centre or luncheon club)	1	2	3
b. Women's support group/club	1	2	3
c. Men's support group/club	1	2	3
d. Burial society	1	2	3
e. Stokvels (money investment club)	1	2	3
f. Other (specify……			

THANK YOU VERY MUCH FOR YOUR CO-OPERATION

ANNEXURE 2

THE SURVEY QUESTIONNAIRE

IDENTIFICATION DATA

Interviewer's name:…… Preferred Language of respondent……

Data Collection Form No: | | | | | |

Date: (dd/mm/yy) ____/____/_____

Geographical Area:

Urban	Non urban	Province
1	2	

Type of dwelling :

Brick house	Mud house	Shack	Other(specify…
1	2	3	4

INCOMPLETE INTERVIEW LOG:

	Visit 1	Visit 2	Visit 3
Time			
Comment			

Comment codes : Interview completed (1), Appointment made for another day 2

Refused to participate (3), Can't complete interview (4),
Other 5 (Specify**:……**

Interviewer starting time:

Stopping time:

SECTION 1

DEMOGRAPHY

1. Older Person's Biographical Data

1.1. In what year were you born?

1.2. Sex: Male……1
Female……2

1.3. Language: **(as identified by respondent)**

isiXhosa	isiZulu	Sotho	English	Afrikaans	Other
1	2	3	4	5	6

1.4. What is your nationality?:

South African	1
Other: Specify……	2

1.5. What is your marital status?:

a. Married	1
b. Widowed	2
c. Separated	3
d. Divorced	4
e. Never married	5

1.6. From which of the following sources do you derive income (**respondent's only**)?

	Yes	**No**
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2
	1	2

1.7. What is the highest standard you completed at school? **(tick one option only)**

a. No schooling	1
b. Sub A	2
c. Sub B	3
d. Standard 1	4
e. Standard 2	5
f. Standard 3	6
g. Standard 4	7
h. Standard 5	8
i. Standard 6	9
j. Standard 7	10
k. Standard 8	11
l. Standard 9	12
j.Standard 10	13
m. Other: specify……	14

HOUSEHOLD INFORMATION
I am now going to ask you about all the people who live in this household? I only need to know their first names, gender, age and relationship to you.

Interviewer: Complete the grid below for all persons who live in the household. Probe, to check that all co-residents have been mentioned.

Definition of "live in this household": All persons who live in the household (i) at least four months of the year, and (ii) eat from a common pot when they are here.

Person Code	First Name	Gender M or F	Age (years)	Relationship to respondent	Attend school=1 Don't attend= 2 N/A. = 3	Working/employed (earning weekly/monthly salary) Yes =1; No=2; N/A = 3
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						

Gender code: 1= male 2 = female

Relationship to respondent Code: 1= Head of household
2 = spouse, partner
3 = son,
4 = daughter
5 = Grandchild
6 = Mother/father in-law
7 = Son/daughter in-law
8 = Brother/sister in-law
9 = Aunt, uncle
10 = Niece, nephew
11 = Sister, brother
12 = other relative
13 = lodger
14 = Household helper
15 = Father, mother

1.8. Are you the head of this household?

Yes=1	No=2

1.9. How long have you lived in this township/village (in years)?

1. Less than 1year	1
2. 1 =< 2 years	2
3. 2 =< 5 years	3
4. 5 =< 10 years	4
5. >= 10 years	5

1.10. How long have you lived in this house?

1. Less than 1year	1
2. 1 =< 2 year	2
3. 2 =< 5 years	3
4. 5 =< 10 years	4
5. > =10 years	5

1.11. Where does this household get water? **(more than one answer possible)**

	Yes	No
1. From a river/water stream/pond	1	2
2. Tap (inside house)	1	2
3. Tap (in the yard)	1	2
3. Communal tap	1	2
4. Other (Specify……		3

1.12 What type of toilet facility does this dwelling have?

a. Flush toilet inside house.	1
b. Flush toilet in yard.	2
c. Communal flush toilet	3
d. Pit latrine	4
e. Bucket toilet	5
f. Chemical toilet	6
g. No toilet/Not available	7
h. Other (Specify….	8

1.13. Which forms of energy are used in this house? (**more than one answer possible**)

	Yes	**No**
1. Timber/wood	1	2
2. Electricity	1	2
3. Coal/anthracite	1	2
4. Paraffin	1	2
5. Gas	1	2
6. Other (Specify……		3

1.14. I am going to read you a number of statements. Which one best describes your household situation?

	Yes	No
1. Not enough money for basic things like food and clothes		
2. Have enough money for food and clothes, but short on many other things		
3. We have a radio		
4. We have a TV		
5. We have a refrigerator		
6. We have a car		

1.15. How many rooms does this house have ? **(including kitchen but excluding bathroom/toilet)**

1. One room	1
2. Two rooms	2
3. Three rooms	3
4. > Three rooms	4

1.16. From which of the following sources does this household derive its income? **(more than one answer possible)**

	Yes	No
1. Government child support grant	1	2
2. Social old age Pension	1	2
3. Employer Pension	1	2
4. Remmittance from family member(s)	1	2
5. Employed (full-time)	1	2
6. Employed (part time/odd jobs)	1	2
7. Self employed (e.g. hawking)	1	2
8. Donation by private welfare organisation(s) (e.g. church)	1	2
9. No income	1	2
10. Other (Specify…		

1.17. From which of the following sources do you personally derive income? **(more than one answer possible)**

	Respondent	Household
1. Child support grant	1	2
2. Social old age Pension	1	2
3. Employer Pension	1	2
4. Foster care grant	1	2
5. Care dependency grant	1	2
6. Child disability grant	1	2
7. Unemployment insurance	1	2
8. Workmen's compensation	1	2
9. Remmittance from family member(s)	1	2
10. Employed (full-time)	1	2
11. Employed (part time/odd jobs)	1	2
12. Self employed (e.g. hawking)	1	2
13. Donation by private welfare organisation(s) (e.g. church)	1	2
14. No income	1	2

1.18. If you do not derive any income from government, what is the reason(s) for this?

(do not read options)

	Yes	No	Not applicable
1.Don't know where to apply	1	2	3
2. Government offices too far (in Town)	1	2	3
3. Don't have legal papers (e.g. birth certificate; child clinic card ID book)	1	2	3
4. Not eligible	1	2	3
4. Other (Specify…….			

1.19. I am going to read you a number of statements. Which one best describes your household's financial situation? **(Interviewer read the options to respondent)**

1. Have enough for basic necessities	1
2. Sometimes don't have enough for basic necessities	2
3. Often unable to buy basic necessities	3
4. Have to borrow money to survive	4

SECTION 2

I am now going to ask you about your health and well-being

1.20. How would you rate your health at present?
(**read out the options loud)**

1	2	3	4
Excellent	Good	Fair	Poor

1.21. Compared to people of your age, would you say your health is "better", the "same" or "worse" than theirs?

1	2	3
Better	Same	Worse

1.22. Which of the following health conditions do you have at present? Is the condition being treated at a clinic or by a doctor?

Health condition

	Yes, not being treated	Yes, being treated	No	Not sure
1. Stress	1	2	3	4
2. Depression	1	2	3	4
3. Hypertension (high blood pressure)	1	2	3	4
4. Arthritis or rheumatism	1	2	3	4
5. Diabetes	1	2	3	4
6. Eye sight problem	1	2	3	4
7. Hearing problem	1	2	3	4
8. Heart condition	1	2	3	4
9. Stroke	1	2	3	4
10. TB (Tuberculosis)	1	2	3	4
11. Cancer	1	2	3	4
12. Asthma	1	2	3	4
13. Epilepsy (convulsions or fits)	1	2	3	4
14. Stomach ulcer(s)	1	2	3	4
15. Loss of memory	1	2	3	4
16. Kidney problem	1	2	3	4
17. Shortness of breath	1	2	3	4

SECTION 3

HIV/AIDS KNOWLEDGE AND AWARENESS

I am now going to ask you questions about HIV/AIDS

1.23. Do you know what HIV/AIDS is?

Yes	No
1	2

(If No, go to 1.30; if yes, go to1.24)

1.24. I am going to read you a list of statements about AIDS. Please tell me whether you Agree, Disagree or are Not sure with the statement in each case.
(interviewer read options to respondent)

AIDS is…	Agree	Disagree	Not sure
1.A disease caused by a germ(virus)	1	2	3
2.A disease caused by witchcraft	1	2	3
3.A disease caused by poor nutrition	1	2	3
4. Punishment from God	1	2	3
5.Other (please specify…….	1	2	3

1.25. Where did you get your knowledge about HIV/AIDS ? **(read options, multiple responses possible)**

	Yes	No
1. From the TV	1	2
2. From Radio	1	2
3. In Newspapers	1	2
4. In pamphlets/ Magazines.	1	2
5. From Doctor/nurse	1	2
6. Other (Specify…..		

1.26. Do you understand the information given about HIV/AIDS?

Yes	No	Not sure
1	2	3

1.27. In your opinion is it possible to transmit HIV by means of the following?
(read the options loud)

	Yes	No	Don't Know
1.Kissing	1	2	3
2.Sitting on a toilet seat	1	2	3
3.Touching someone with HIV/AIDS	1	2	3
4.Drinking from the same mug	1	2	3
5.Breathing the same air as an HIV+ person	1	2	3
6.Exchanging bodily fluids	1	2	3
7.Unprotected sex	1	2	3
8. Other(specify…….			

1.28. Can older persons be infected with HIV?

Yes	No	Not sure
1	2	3

(If No go to 1.30; If not sure, go to 1.30; if yes go to 1.29)

1.29. How can older persons protect themselves from being infected with HIV? **(Do not prompt)**

	Yes	No	Don't know
1.Wear protective gloves when cleaning clothes and washing a sick person with AIDS	1	2	3
2. Use a condom if sexually active	1	2	3
3. Drinking traditional herbs (muti)	1	2	3

SECTION 4

I am going to ask you about your caregiving to an adult person(s)in this household (someone who is 18-49 years old). **By caregiving I mean**: cooking, feeding, washing, providing medication, taking the sick person to a doctor/clinic or hospital because the person is unable to do these tasks him/herself.

1.30. Are you presently caring for a young adult in this household (between 18 and 49 years) who has been sick for a long time?

Yes	No
1	2

(If No, go to 1.44 ; if yes,go to 1.31)

1.31. Are you presently caring for an adult family member(s) who is (are) has AIDS - who is either living in this house or elsewhere?

Yes	No
1	2

1.32. Is there someone who helps you with daily caregiving to the sick person(s) with HIV/AIDS?

Yes	No
1	2

(if No, go to 1.35; if yes go to 1.33)

1.33. If Yes, who is this person(s)?

	Yes	No
1. My husband/partner	1	2
2. My other child(ren)	1	2
3. My grandchild(ren)	1	2
4. NGO/CBOs (counselors; home carers; home visitors)	1	2
5. Community nurse(s)	1	2
6. Nurse Aid	1	2
7. Neighbour(s)	1	2
8. Other relative	1	2
9. Friends	1	2
10. Other (Specify…		3

1.34. What type of help or support does this/these person(s) provide?

(more than one answer accepted)

Support provided	Yes	No
1. Financial	1	2
2. Washing the PLWHA	1	2
3. Feeding	1	2
3. Administering Medication	1	2
4. Transporting PLWHA to health facility	1	2
5. Emotional/spiritual	1	2
5. Other (Specify……..		3

1.35. Are there things you would like to learn to improve your caregiving activities?

Yes	No
1	2

(If No, go to 1.37; if yes go to1.36)

1.36. If Yes, which of the following will be of help to you? **(more than one answer possible)**

	Yes	No
1. Learn more about HIV/AIDS	1	2
2. Learn how to better care for a PLWHA	1	2
3. Guided on how to access government assistance to care for the PLWHA	1	2
4. Other (Specify……..		3

1.37. On average how often in the past year have you sought medical treatment for the PWHA in your household ? **(read options to respondent)**

a. 2-3 times a month	1
b. Once a month	2
c. Less often than once a month	3
d. Other (specify……	4

1.38. How helpful overall do you find the health providers at the clinic/hospital when you visit with the PLWHA?
(If never visited clinic/hospital with PLWHA, go to 1.39)

a. Very helpful	1
b. Helpful	2
c. Unhelpful	3
d. Very unhelpful	4

1.39. Is there somebody else in your family who knows about the PWHA's condition?

Yes	No
1	2

(If No, go to 1.41; If yes go to 1.40)

1.40. If Yes, who is this?
Person(s) who knows

	Yes	No	Don't know
1. My partner/husband	1	2	3
2. My other child(ren)	1	2	3
3. My grandchild(ren)	1	2	3
4. My sister/brother	1	2	3
5. My mother/father	1	3	3
6. Other (Specify…			

1.41. How do other members of your household behave towards the PLWHA? **(answer each) ?**

	Yes willingly	Yes reluctantly	No
1.They share meals with him/her	1	2	3
2.They share the same room with him/her	1	2	3
3.If no, why? (explain….			

1.42. Do people in the neighborhood know about the PLWHA condition? **(answer each)**

	Yes	No
1. Only one person knows	1	2
2. Some people know	1	2
3. It is common knowledge	1	2
4. Nobody knows	1	2
5. Don't know		3

1.43. During your caregiving of the PLWHA, does s/he ever? **(answer each)**

	Yes everytime	Yes sometimes	No/ Never
1. Shout or get angry with you	1	2	3
2. Hit or throw things at you	1	2	3
3. Accuse you of being responsible for his/her illness	1	2	3
4. Refuse to talk to you	1	2	3
5. Refuse to take food from you	1	2	3

1.44. Which other person(s) in this household who are sick (but not with AIDS) do you care for ? **(interviewer refer to the household grid for person code P3)**

Person	Code
1.	
2.	
3.	
4.	
5.	

I am now going to talk to you about person(s) in this household who have died in the last two years.

1.45. To your knowledge, is there someone in your household who died from AIDS in the past two years?

Yes	No	Not Sure
1	2	3

(If No, go to 1.48 ; If Not sure, go to 1.48 ; If Yes, go to 1.46)

1.46. What relationship was this (these) person(s) to you? **(multiple answers possible)**

	Yes	No
1. Child(ren)	1	2
2. Husband	1	2
3. Grandchild	1	2
4.Other (……		

1.47. On average how many months did you care for this/these person(s) before she died (PLWHA) from the time s/he/ they started to be sick with AIDS?

a. Less than one month	1
b. 1= < 4 months	2
c. 4 =< 7 months	3
d. 7 = < 10 months	4
e. > =10 months	5
f. Don't know	6

1.48. Did the person(s) who died live in this house all his/her life?

Yes	No
1	2

(If No, go to 1.49; if yes, go to 1.50)

1.49. If No, where did s/he/they live when s/he/they started to be sick with AIDS?

a. In another country	1
b. In the city/an urban area	2
c. In a rural area	3
d. Don't know	99

1.50. From whom did you first learn or hear about his/her/their illness?

a. From him/her/them	1
b. From a nurse/doctor at clinic/hospital	2
c. From a CHW (Community Health Worker)	3
d. From his/her partner	4
E. Other (specify….	5

1.51. Did this/these person(s) previously contribute to the household financially?

Yes	No
1	2

(If No go to 1.53; If yes, go to 1. 52)

1.52. Do you agree or disagree with the following:

	Agree	Disagree	Not sure
1. His/her death affected the household's finance severely	1	2	3
2. His/her death affected the household's finance moderately	1	2	3
3. His/her death did not affect the household's finance at all	1	2	3

SECTION 5

CARING FOR THE ORPHANS/GRANDCHILDREN

I am now going to ask you about the grandchildren you are caring for in this household (By caring I mean:cooking, feeding, washing, emotional, minding, counselling, disciplining, helping with school work, playing etc).

1.53. Are all your grandchildren at school?

Yes	No
1	2

(If No, go to 1.54; If Yes, go to 1.55)

1.54. If some are not at school, why are they not at school?
(more than one answer possible)

	Yes	No
1. There is not enough money for school	1	2
2. They (s/he) refuse to go to school	1	2
3. They (s/he) are too young to go to school	1	2
4. They (s/he) have finished school	1	2
5. They (s/he) are sick/disabled	1	2
6. They (s/he) are HIV infected	1	2
7. Other (Specify……	1	2

1.55. Who pays for their school fees and uniforms? **(more than one answer possible)**

	Yes	No
1. I pay for them	1	2
2. Other members of the family	1	2
3. Child support grant	1	2
4. Nobody pays for them/have no uniforms	1	2
5. Other (Specify……	1	2
6. Don't know		

1.56. Why are you caring for these child(ren) ?

	Yes	No
1. I have no choice	1	2
2. Nobody else will/to care for them	1	2
3. They are part of my family	1	2
4. Other (specify…….		3

1.57. In which area(s) of caring for these children do you need support or help, and how much? **(read each option loud)**

Caring activity	**A lot of support/help**	**Some support/help**	**Don't need support/help**
1.Financial	1	2	3
2.Physical	1	2	3
3.Emotional	1	2	3
4.Social (e.g. discipline)	1	2	3
5.Other (specify…….	1	2	3

1.58. Which area(s) in which you spend money caring for the children are most costly; costly and least costly? **(interviewer must read options)**

Caring activity	**Most costly**	**Costly**	**Least costly**
1.School fees and uniforms	1	2	3
2. Health care	1	2	3
3. Food	1	2	3
4. Clothes	1	2	3
5. Transport	1	2	3
5. Other (Specify…….	1	2	3

1.59. Is there a grandchild(ren) who has been diagnosed with HIV in this household?

Yes	**No**	**Don't know**
1	2	3

(If No, go to 1. 61; If Don't know, go to 1.61; If Yes, go to 1.60)

1.60. If Yes, what are the major care needs of this (these) child(ren)? **(do not read the options to respondent)**

	Yes	**No**
1. Access to treatment (medication) for their condition	1	2
2. Counselling/emotional support	1	2
3. Nutrition support	1	2
4. Education (inform and encourage them about importance of taking treatment everyday)	1	2
5. Other(Specify……	1	2

SECTION 6
LOCAL/DISTRICT GOVERNMENT AND GENERALSUPPORT

Now I will ask you about the type of support you receive from government which helps you with your caregiving (by support I mean: government grants; free medicine; transport to clinic/hospital; food parcels)

1.61. Do you receive any support from government places (eg. Clinic; municipal offices)?

Yes	No
1	2

(If No, go to 1.63; if yes go to 1.62)

1.62. If Yes, indicate how much you agree or disagree with the following statement **(read each statement and circle the appropriate code)**

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1.The support I received from government is sufficient	1	2	3	4	5
2.The support I received from government is not sufficient	1	2	3	4	5
3.The support from government meet the basic needs of my caregiving	1	2	3	4	5
4.Government need to put more support for people who care for the PLWHA	1	2	3	4	5

1.63. If No, Which of the following support will help you meet your caregiving needs? **(read each option and circle the appropriate answer)**

Type of support

	Yes	No	Not Applicable
1. Nutrition (e.g.Food parcels)	1	2	3
2. Financial or money vouchers	1	2	3
3.Provide more room/space for people who care for PLWHA	1	2	3

1.64. To what extent do you agree with the following statements? **(read each statement)**

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
1.Government is committed to support PLWHA and those affected by HIV/AIDS	1	2	3	4	5	6
2.Government provide sufficient money to fight HIV/AIDS	1	2	3	4	5	6
3.Government provide enough support to households affected by HIV/AIDS	1	2	3	4	5	6
4.Government provides enough support to children affected by HIV/AIDS	1	2	3	4	5	6

Now I want to know about other forms of support other than from government that you receive

1.65. Do you belong to a faith/religious body?

Yes	No
1	2

(If No go to 1.68; if yes go to 1.66)

1.66. If Yes, to which faith/religious body do you belong?

a. Zion Christian Church (ZCC)	1
b.Catholic Church	2
c. Anglican Church	3
d. Methodist Church	4
e. Black Independent Church	5
f. Old Apostolic Church	6
g. Other religions:(specify……..	7

1.67. How often do you visit your place of worship?

a. Every Sunday	1
b. Twice a month	2
c. Once a month	3
d. Twice a week	4
e. Stop attending because of my caregiving responsibilities	5
f. Other (Specify…..	6

1.68. Do you belong to any of the following groups? **(read options to respondent)**

	Yes	No	Not applicable
1. Volunteer/Community support group (e.g. sewing group)	1	2	3
2. Women's support group	1	2	3
3.Men's support group	1	2	3
4. Burial society	1	2	3
5. Stokvels (money investment club)	1	2	3
4. Other (specify…….			

THANK YOU VERY MUCH FOR YOUR COOPERATION